

White Paper

## Living with a long-term condition – the adolescent experience

*Adherence challenges and solutions in adolescents,  
with a focus on rare disease*

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# Executive summary

Adolescents who are living with a chronic health condition face unique challenges that can make it especially difficult for them to adhere to a prescribed treatment or healthcare regimen. While individual situations and responses will vary, there are common things that many teenagers are trying to navigate as well as managing their disease, such as growing independence, increased pressure at school and seeking social acceptance, and overcoming stigma, which can impact all adolescents' ability and/or motivation to achieve optimal disease self-management. These challenges can be further compounded when the condition is rare, as much-needed social and system support is often not forthcoming with such diseases.

It is also important to acknowledge that adolescence is a key period for establishing long-term behavioural habits that can enhance or hinder outcomes. Understanding which type of support can best address identified challenges and foster sustained positive behaviour change is critical to improving quality of life and disease outcomes in both the short and long term.

In this paper, we explore these challenges and their impact, and also provide a series of recommendations on how support services can most effectively address the needs of this population, leveraging academic evidence along with insights and considerations from IQVIA digital, nurse, and behavioural science experts who are currently working with these groups.



## Introduction: adherence in adolescence

Adolescents who are living with and managing a chronic condition face unique challenges that make effective disease self-management particularly difficult. Not only can the rapid growth and physiological changes associated with adolescence produce unusual disease patterns and symptom presentation, but also ongoing psychosocial development can have a negative effect on the emotional and cognitive processes that affect adherence to self-management behaviours.

In this paper, we use the term 'adolescent' to mean people aged between 10 and 19 years.

Managing illness often involves a range of health-related behaviours, including adherence to drug regimens, dietary restrictions, and requirements for physiotherapy. Many healthy behaviours, such as taking exercise and the avoidance of smoking and drinking alcohol, can be even more important for teenagers who have additional medical needs. However, adolescence is also a high-risk time for these types of behaviours, potentially impacting overall clinical outcomes.

These challenges are often greater if the chronic condition is rare, as intervention may be especially important if much-needed social and system support is not forthcoming.

A disease is deemed to be rare if it is one that affects fewer than 1 in 2,000 people in the general population, but research shows that rare diseases are not actually rare: in the UK alone, 1 in 17 people will suffer from a rare disease at some stage in their life, meaning that more than 3 million people will have one at some point. Of those, at least 50% of new cases start in childhood.<sup>1</sup>

In order to optimise treatment management behaviours and disease outcomes, the challenges posed by adolescence and rare diseases need to be identified and systematically addressed by both patients and their care teams.

## Scope of the problem

It is difficult to determine the prevalence of rare diseases among adolescents because of a lack of population-specific data. However, there is more information available about chronic conditions in general. According to the World Health Organization, as many as 15% of adolescents are living with at least one chronic condition.<sup>2</sup>

Among such adolescents, non-adherence is a prevalent and serious concern.

According to the literature, the rate of non-adherence among adolescents is comparable with that in the general population, meaning that 50% of those with a long-term condition do not comply with care recommendations.<sup>3,4</sup> For those living with a rare condition and insufficient access to the information and support they need, achieving adherence may be even more challenging.



Chronic diseases and their treatments place varying degrees of psychological and behavioural demands on adolescents, meaning that although rates of adherence differ by disease type, they are prevalent for all diseases (Table 1). For example, studies show that approximately 38% of adolescents with epilepsy are non-adherent,<sup>5</sup> while some 57% of adolescents with asthma fail to take the prescribed doses of inhaled medication.<sup>6</sup> Furthermore, adherence levels vary within a single treatment regimen. Johnson and colleagues found that among a sample of adolescents with type 1 diabetes, 25% were neglecting insulin injections, 29% were not monitoring their glucose levels, and 81% were not following the recommended diet.<sup>7</sup>

Disease management often requires enactment of multiple and qualitatively different behaviours that can be challenging at any age, but even more so during adolescence.

Poor adherence can have many negative effects. For example, it is associated with medical complications

and adverse events that result in more frequent visits to the emergency department. In fact, hospital admission rates are as much as 69% higher for patients with a chronic condition who are non-adherent compared with those who are adherent.<sup>8</sup>

Not only do these outcomes result in reduced quality of life for the patient – in terms of consequential fatigue, social withdrawal, and/or absence from school – but they can also threaten the well-being of other family members: unplanned medical visits are time-consuming, often require flexibility in family members’ schedules, and may incur additional medical or other expenses; together these can cause significant additional stress.<sup>9</sup>

As well as these short-term effects, poor adherence during adolescence can also have detrimental effects in the longer term, contributing to an increase in both morbidity and mortality.<sup>10</sup>

## Key barriers to adherence for adolescents with a rare chronic condition

For patients with a chronic condition, the process of transitioning from paediatric to adult health services is often associated with a deterioration in health. Despite this, the challenges specific to this part of the disease journey are often left unaddressed by the care team and the support interventions available.<sup>16</sup>

In the following section, we describe the key, evidence-based barriers to adherence for these individuals. We start by highlighting the challenges shared across all adolescents with a chronic condition, and then we describe those that are unique to people living with a rare disease.

We utilise the capability, opportunity and motivation model of behaviour (COM-B) to organise the insights. COM-B is a theoretical model that aids the understanding of the barriers to and facilitators of behaviour. The model divides these behavioural drivers into three categories: capability, opportunity, and motivation.<sup>17</sup>

All three categories directly influence behaviour; capability and opportunity can also indirectly affect behaviour through their impact on motivation. This categorisation is important as it allows us to consider the right kind of intervention/support for different factors, aligned to their category.<sup>17</sup>

### Capability

In the context of adherence, the ‘capability’ arm of the COM-B model refers to people’s psychological and physical capacity to adhere to their recommended treatment.<sup>17,18</sup>

Adolescents share many of the psychological and physical barriers to adherence that are experienced by typical adult patients. For example, a treatment may be difficult to understand because of its complexity, or the actual consumption of a medication may be challenging because of the size of the pill or the taste of the medicine.

**Table 1: Adolescent non-adherence rates**

| CONDITION                                  | ESTIMATED RATE OF NON-ADHERENCE AMONG ADOLESCENT PATIENTS (%) |
|--|---|
| Epilepsy <sup>5</sup>                      | 38  |
| Asthma <sup>6</sup>                        | 57  |
| Growth hormone deficiency <sup>11</sup>    | 42  |
| Cystic fibrosis <sup>12</sup>              | 32  |
| Type 1 diabetes <sup>13</sup>              | 65  |
| Human immunodeficiency virus <sup>14</sup> | 59  |

Because adolescence is a key period for forming habits, it is critical that patients use this time to create routines and practise health behaviours that optimise self-management of their disease. When adolescents manage their disease poorly during the early years of treatment, they are often left unprepared for the transition to adult services and may be faced with worse disease outcomes during adulthood.<sup>15</sup>





However, adolescents also face challenges that are specific to them as individuals experiencing the physical and emotional transformations of puberty. Rapid physical changes can cause unusual disease patterns that make it difficult to establish a consistent response to symptom presentation, while growing susceptibility to stress and other mental health issues can negatively impact their ability to prioritise treatment.<sup>2</sup> For example, anxiety may reduce a person's cognitive capacity to remember the demands of a treatment regimen, while depression may result in general disinterest and low investment in the treatment plan.<sup>9</sup>

In addition, adolescents are only just beginning to learn how to organise themselves and prioritise the competing demands of a range of activities (e.g. school, extracurricular activities, employment, social commitments). It is hard enough for most adults to juggle all the pressures on their time, but during adolescence, the skills to cope with and effectively manage multiple demands are, for many, still in development. Adolescent patients report that having so many competing priorities can make maintaining a routine and simply remembering to administer medication very difficult.<sup>9,19</sup>

Adolescents living with a rare disease face additional barriers to adherence. Patients who have one of the more common chronic conditions can usually rely on their healthcare professional (HCP) to tell them how to manage their disease and its treatment. However, for patients with a rare disease, this may not be the case. An HCP may have limited experience of treating a disease with such a low prevalence, and the responsibility to self-educate will fall on the patient.<sup>20</sup> Although patients report trying to become experts on their own condition, the quality of the information on the internet about rare diseases is low.<sup>21</sup> When patients cannot gain a clear understanding of how to manage their disease or treatment, they are at increased risk of non-adherence.<sup>18</sup>



*'It was my first year of marching band... And I told you the schedule, twice a week plus competitions, three-hour rehearsals... I would be tired, and I didn't want to do my treatments because I'm working on my homework and it's like one in the morning... And I'm just like, oh my god... I cannot take this anymore; this is too much.'*

— Adolescent patient with cystic fibrosis<sup>22</sup>

## Motivation

The 'motivation' arm of the COM-B model is related to the brain processes that inform adherence, including habitual activities, emotional responses, and analytical decision-making.<sup>17,18</sup> Because adolescence is a period of significant cognitive development that results in unique, emotional responses to being tasked with the management of a chronic condition, adolescents are particularly susceptible to motivation-related challenges.

First, adolescence is a critical time for the development of one's concept of self. As adolescents are trying to discover who they are and determine the type of person they want to be, many are resistant to having to add 'chronic disease patient' to their identity. This resistance can lead to a denial of the illness that manifests itself in low motivation to adhere to treatment recommendations.<sup>9</sup>

Second, the ongoing development of the adolescent brain can pose a threat to adherence. Not only do adolescents have underdeveloped impulse control that may be associated with rebelling against the advice coming from healthcare providers and caregivers, but they also have limited risk-assessment skills, which

make it hard for them to accurately evaluate the threat of a hypothetical situation.<sup>9</sup> Because they rely more on concrete than abstract thinking, many adolescents are unable to fully comprehend or foresee the long-term consequences of non-adherence (i.e. being more focused on the drawbacks of treatment in the present), and are consequently more likely to misperceive the severity of their disease and the necessity for treatment.<sup>9</sup> When people do not understand how serious their illness is or how critical its treatment is, they are likely to have insufficient motivation to self-manage it.

*'I take my inhaler, but I'm playing around with the rest of it [treatment regimen] because I don't really need to take it. I don't feel the need to take it because, as I am now, I can run about fine and everything and just don't really need to take it.'*

— Adolescent patient with asthma<sup>23</sup>

Finally, adolescents may be reluctant to adhere to a treatment regimen because of knowing about and fearing potential side effects. While this is a concern for patients of all ages, adolescents may possess an elevated fear of experiencing side effects that elicit noticeable cosmetic changes. For example, some adolescents with type 1 diabetes report intentionally omitting their insulin as a strategy for weight control, and some patients with asthma are resistant to taking their medication because of its potential to cause acne.<sup>6,24</sup>

The uncertainty surrounding rare diseases specifically can result in emotional responses that put an adolescent at risk of non-adherence. Not only is it emotionally draining for patients to wait years for the right diagnosis, but there is no guarantee that receiving one will offer them clarity. Little may be known about their particular disease.<sup>25</sup>

When this is the case, adolescents have no sense of what to expect and can fall into 'mental traps' that distort their perceived value of treatment.<sup>26</sup> Beyond that, compared with those with more common chronic conditions, patients with rare diseases are more likely to suffer from both depression and anxiety – two mood states/disorders associated with adherence.<sup>17,27</sup>



## Opportunity

The third component of the COM-B model, 'opportunity', is defined as all the factors outside of one's individual self that either facilitate or impede adherence.<sup>17,18</sup> Opportunity factors reported by adolescents include the availability of social support and transitioning from paediatric to adult health services.

**Social support can come in many forms, but the extent and quality of support from peers, parents, and HCPs is especially predictive of adherence among adolescent patients.<sup>19,28</sup>**

During adolescence, individuals strive to conform with the 'norm', but having a chronic disease inevitably makes them feel different. As well as feeling different, adolescents can also experience overt stigma because of their condition. For example, young people with inflammatory bowel disease report feeling

embarrassed when peers have reacted with mockery or disgust on learning about their condition, and these experiences have been associated with lower treatment adherence.<sup>29,30</sup> Others describe having to take medication in front of other people their age as a major concern.<sup>31,32</sup> Given that many treatment regimens, such as those for diabetes or cystic fibrosis, require meal-time medication to be taken at school, it is easy to understand how the perceived pressure to be accepted by one's peers influences rates of adherence.

Conflict between adolescent patients and their parents can also contribute to non-adherence, and one of the main reasons for conflict comes from poor delegation of responsibility during the transition to adulthood. As adolescents get older, they strive for autonomy and are eager to take control over their own treatment. However, some parents find it very difficult to 'let go'. When parents continue to interrupt this shift in responsibility or over-monitor the process, it can leave patients feeling uncomfortable and put them at risk of non-adherence.<sup>19</sup>

While granting adolescents space to establish their own routines is important, stepping away all at once can be interpreted by adolescents as having parents who 'don't care'. It is therefore important that adolescents continue to feel supported during this phase of life.<sup>19</sup> The characteristics of an unsupportive parental relationship include poor communication, unclear expectations, ineffective problem-solving skills, and a lack of flexibility – all of which are associated with lower rates of adherence to self-care behaviours.<sup>33</sup>

Beyond the patient–parent relationship, the quality of the overall home environment can also affect rates of adherence in adolescents. Any degree of dysfunction related to, for example, parental mental health problems, family violence, or substance abuse, makes treatment adherence extremely challenging for an adolescent.<sup>9</sup>

Young children with a chronic illness experience the healthcare system under the supervision of a parent or other adult caregiver.

As these children grow older and transition to a more independent, patient-centred system, many factors can

negatively affect their treatment adherence.<sup>34</sup> Not only do many patients experience anxiety as a result of an unfamiliar care team, undefined degree of control, or unexpected changes to therapy, but they can also face system-level difficulties relating to the limited availability of specialty clinicians or uncoordinated transfer of medical records.<sup>34</sup>

When the transition from paediatric to adult services is not well supported, factors such as these can induce a combination of confusion and frustration that severely threatens adherence.

Finding social support may be especially difficult for patients with rare diseases. While a teenager with diabetes can seek support from one of the many online communities that exist, approximately 50% of rare diseases do not have a specific support foundation.<sup>35,36</sup> In fact, patients with rare diseases may live their entire life without meeting another person with the same condition.<sup>17,18</sup>

This feeling of isolation and stigma can contribute to a fear of disclosure. Some patients worry that being open about their condition will subject them to rejection from others and force them to deal with more questions and inappropriate comments. They choose to conceal their condition instead and hope that this will allow them to 'fit in' and avoid being treated differently.<sup>37</sup>

There are challenges that extend beyond the disease itself and can, at times, be overwhelming. These challenges can include:

- accessing appropriate care and treatment during the many years it can often take to receive a correct diagnosis
- coping with the emotional challenges a rare disease presents, which include feelings of uncertainty and loneliness
- handling the financial aspects of a rare disease, which can be exacerbated by bills for special care and travelling to find specialists.<sup>38</sup>





However, the problem with prioritising concealment is that disclosure is important for receiving helpful social support. People need to understand what someone's condition is and what their unmet needs are in order to provide them with the type of emotional and practical support that will drive adherence.<sup>37</sup>

In addition, patients with rare diseases may be especially susceptible to the consequences of an unsupported transition to adult care. Most rare diseases affect multiple body systems, meaning that many different types of professionals are involved in patients' treatment. Not only do patients report feeling 'lost' amid the efforts to coordinate communication across so many specialists, but some also feel completely 'cut off' – as if no single HCP wants to take responsibility for them.<sup>25,39</sup>

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*“On first meeting, I don’t think that I would ever tell anybody... I suppose it’s easier to say, “I’ve got a tummy ache”, or “I’ve got a bug” or something if you’re not feeling well... ‘cause you’ve got to gauge how they’re gonna react, you know... If you just suddenly blurt out, “I’ve got ulcerative colitis”, they might go, “Urghh”, you know, “What’s that? Is it infectious?”... and not want to know you...”*

— Adolescent patient with ulcerative colitis<sup>29</sup>

## How can we help adolescents to self-manage better?

Given the unique challenges that adolescent patients face when it comes to self-management, it is critical that the support they are offered is evidence-based and tailored to their specific needs. This is as true in rare disease as in more common conditions. Below, we examine a variety of strategies that can be used to

overcome the challenges identified and, ultimately, to improve self-management behaviour.

## Opportunities for impact

### EDUCATION PLUS BEHAVIOURAL SUPPORT

If adolescent patients are to understand how to self-manage their condition, it is critical that they are thoroughly educated about their diagnosis and the negative effects of non-adherence. However, educational interventions alone are insufficient to promote adherence among adolescent patients with a chronic condition.<sup>40</sup> Rather, repeated education should be combined with a number of different behavioural strategies.

### REMINDERS

Having to remember to take medication every day can be daunting for adolescents, but receiving reminders can help. The use of text messages and mobile phone apps to alert patients when they need to take medication has been found to be feasible and acceptable and to increase adherence across a variety of therapeutic areas.<sup>15</sup> Not only are reminders associated with increased rates of adherence, but they are also predictive of improvements in self-reported quality of life and self-efficacy.<sup>41</sup>

The relationship between the use of reminders and self-efficacy is especially strong when the messages that patients receive are specifically tailored to them.<sup>42,43</sup> Tailoring messages involves conducting an assessment of the individual and customising the content of that person's messages according to relevant criteria, such as their illness and treatment perceptions.

### SELF-MONITORING TOOLS

Providing adolescents with tools that facilitate self-monitoring can help them establish a routine, which is a key predictor of optimal self-management. Developing and maintaining a structured medication list, dosing schedule, and/or symptom diary is associated with improvements in adherence.<sup>41,44</sup>

### GAMIFICATION

Given how much time adolescents spend using mobile phones every day, researchers have recently

prioritised the development of mobile health (mHealth) interventions to enhance chronic disease self-management among this target population. Interactive games, especially those that utilise a reward system or offer incentives, have been shown to improve the self-management of conditions such as type 1 diabetes.

### PEER SUPPORT

Peer support interventions can also improve rates of adherence among adolescent patients and can be particularly helpful in rare diseases. An intervention targeting adolescents with systemic lupus erythematosus found that providing patients with an online social media forum, where they could ask questions and share their experience with other patients like themselves, significantly improved rates of adherence.<sup>44</sup> In addition to improving adherence, connecting with other patients who have the same disease can help adolescents navigate daily life and the transition to adulthood.<sup>45,46</sup>

### NAVIGATING THE HEALTHCARE SYSTEM

Boosting confidence to navigate the healthcare system and get the most out of appointments can help to address opportunity barriers, which can be particularly challenging for people with rare diseases. Help can include how to prepare for medical appointments, highlighting what the adolescence should expect from their HCP, and building confidence to ensure their personal needs are being addressed.

### COGNITIVE BEHAVIOURAL THERAPY

Barriers to adherence aligned to the 'motivation' arm of the COM-B model are typically challenging for adolescents to overcome because many stem from their stage of cognitive development. However, there is evidence to suggest that providing patients with training that is grounded in cognitive behavioural therapy is a promising way to improve self-care behaviours while also diminishing disease-related stress.<sup>47</sup> Cognitive restructuring of unhelpful beliefs and the implementation of practical problem-solving exercises may be especially useful.<sup>47,48</sup>

## SUPPORTING PARENTS ALSO SUPPORTS THEIR CHILDREN

It is important to consider that the transitional period of adolescence can also have an impact on parents/caregivers. Trying to find the right balance between 'letting go' to promote autonomy, on the one hand, and providing a safety net to reduce risk, on the other, can be a challenge – but getting it right has been shown to be positive for adolescents' adjustment during transition.<sup>4</sup> It is therefore important to offer support to parents/caregivers as well as to their children as they negotiate managing these changing responsibilities together.

## The digital opportunity

As we have seen, technology is a promising channel for delivering interventions that target disease self-management by adolescents. Not only does a digital intervention allow for the integration of many tools and repeated exposure to users, it also offers greater opportunities for accessing additional support.<sup>15</sup>

Below, Sumit Sharma, Senior Director of Technology Offerings at IQVIA, describes the ever-increasing role of digital platforms in adolescent health management.



According to research from US-based think tank the Pew Research Center, almost 90% of adolescents in the USA have access to a smart phone and spend an average of 6 hours per day using it.<sup>49</sup> Their primary method of interaction is text messaging and at least one form of social media, such as Instagram or Facebook. It is therefore not surprising that many clinical studies use social media or digital channels to recruit young adults/adolescents, and that they note that this could be a primary strategy to generate more contacts without using up a significant amount of staff time.<sup>50</sup>



Smartphone apps focus on specific therapy areas, aiming to help with symptom tracking, adherence to medication, post-treatment follow-up, and other health behaviours. More than 90% of adolescents report using text messaging and social media as their primary digital channels for engagement, and studies have found effective strategies for engaging adolescents in digital health to include personalisation<sup>51</sup> and targeted, prompting text messages<sup>52</sup> to help change behaviours.



Each country's laws are different, and in some cases different states within a country have different laws on managing the data privacy of patients. In addition, a clinical study and a patient support programme might have differing needs in their management of the privacy of the adolescents they are working with. Consent might be limited to those aged 18 or 19 years or older, or parental/guardian consent might be required for those younger than 18 years. Matters become further complicated in cases where there is joint custody of an adolescent. Apps should be flexible enough to accommodate these variations between countries, families, and specific studies and programmes. Patients must re-consent once they come of age.



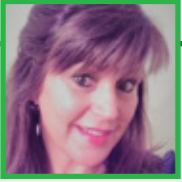
However, privacy is a big concern among those in Generation Z (classified generally as those born between 1997 and 2012). Adolescents trust their parents/guardians and caregivers to help keep their information private and secure. All modern digital health apps must be designed with data privacy as the first consideration. Managing data privacy when engaging specifically with adolescents via digital health is a complex affair. The apps must therefore be technically able to give parents or guardians access to some or all personal health information, or exclude them from most or all entirely. Older adolescents will engage better with digital health when they are more in control of their personal health information.



The next generation of digital health for adolescents will focus not only on engagement, but also on treatment options for conditions such as attention deficit hyperactivity disorder, although data privacy and appropriate technical security must continue to evolve.

## What is it really like to support adolescents?

While it is critical to know which self-management tools and strategies adolescents will find engaging, it is equally important to understand what works from the perspective of those who are providing support directly to these individuals. Bernie Healy is an IQVIA patient support programme nurse who is currently supporting adolescents living with cystic fibrosis, a rare genetic pulmonary disorder. Below, Bernie describes her experience of working with this patient population and her perspective on important support considerations



## Q&A with Bernie Healy, Nurse Adviser

### Q. IN YOUR EXPERIENCE, WHAT ARE SOME OF THE KEY CHALLENGES THAT ADOLESCENTS WITH A CHRONIC ILLNESS FACE IN MANAGING THEIR CONDITION?

**A.** In my experience to date, I have found that one of the main challenges such adolescents face is the 'workload' or 'burden' they encounter on a daily basis. While friends/peers are enjoying life, various activities, or even a lie-in (which most teenagers do), the young people in this cohort are preoccupied by ongoing physiotherapy, nebulisers, medication management, and potential side effects. The teenage/adolescent years can be challenging enough for a person without cystic fibrosis – coping with a surge of hormones and emotions – so having an illness that requires close monitoring and continuous treatments and therapies can contribute to them feeling weighed down and, at times, overwhelmed.

### Q. WHAT IN PARTICULAR IMPACTS ADHERENCE AMONG ADOLESCENT PATIENTS?

**A.** This very much depends on the individuals themselves, their understanding of their illness, and the importance of ongoing adherence, as well as the potential negative connotations that non-compliance may have on their overall well-being. Starting secondary/high school can have a huge impact on this age cohort, and not always a positive one. Many go from relatively small primary schools to the anonymity of a much larger secondary school, which, in itself, can be daunting. This, coupled with the desire to 'fit in' and become 'one of the crowd', can overshadow the importance of taking their medications, undergoing their physiotherapy, or attending appointments. Their desire to be the same as their friends and peers often outweighs the implications of non-compliance, and at this age, when they feel most infallible, they fail to see the bigger picture. Adverse or side effects

of medication can also hinder compliance. Even those effects that HCPs may see as positive (e.g. weight gain) are not considered beneficial by people of this age, and can result in patients skipping or missing doses on purpose.

### Q. WHAT HAVE YOU DONE AND/OR WHAT ARE YOU CURRENTLY DOING TO SUPPORT ADOLESCENT PATIENTS WITH THEIR SELF-MANAGEMENT?

**A.** I believe that positive relationship-building and mutual trust from the outset (visit one), which strengthens over subsequent visits/calls, is pivotal to the supportive role we play on a daily basis. In my role as a nurse adviser on a patient support programme, I initiate many patients on treatment and so am with them throughout the first year of their treatment journey. I make a conscious effort to involve them from the 'get-go' and to talk *to* (as opposed to *at*) them during all of our interactions. I take the time to find out their interests (e.g. sport, the team they follow) and ensure I refer to this on each visit, especially at [Union of European Football Associations] Champions League time – I have quite a few Liverpool supporters! I also use motivational interviewing techniques, especially if non-compliance is flagged as an issue, and use reflective practices where we look back at how life was before treatment compared with how it is/how they feel now. It's human nature that they forget how ill they may have been when they are feeling well, so I use this to encourage them to continue and maintain a 'normal health state'. Actively engaging patients and regularly checking in with them and their parents/carers has resulted in many parents commenting about how involved their child feels as a result of being part of the overall process, which aids significantly in their ongoing understanding and subsequent adherence to treatment.

**Q. WHAT DO YOU THINK PHARMACEUTICAL COMPANIES COULD DO TO SUPPORT ADOLESCENT PATIENTS BETTER?**

**A.** 1. Patient support programmes that allow sufficient time and resources to support these adolescents.

2. Support patient forums where patients can voice opinions, ask questions, and get feedback from their peer groups.
3. Adapt product materials to age-appropriate levels to ensure interest and understanding.
4. Support information meetings with speakers who adolescents can relate to.

## Conclusions

The number of adolescents living with and managing a chronic condition has increased steadily over the past 20 years. This is partly due to the rising prevalence of obesity and asthma, and partly to medical advancements that have extended the life expectancy of patients with diseases that historically had low survival rates. Furthermore, advances in diagnostic testing and new therapeutic options for rare genetic conditions mean that an increasing number of children are living with and receiving treatment for a chronic condition.<sup>53</sup>

Despite clinical breakthroughs, however, sustained behaviour change related to treatment adherence has yet to be achieved. Poor disease management among the adolescent population remains a serious problem and contributes to poor quality of life, disease complications, and mortality.<sup>9</sup>

Although the barriers to adherence that adolescents with a chronic condition face are multifaceted, evaluations of existing programmes suggest that certain intervention features can effectively overcome many of the frequently reported challenges. Based on the research conducted to date, the integration of educational, behavioural, and cognitive strategies into a programme that provides a digital platform for social support is a promising way of achieving adolescent self-management.

Recognising the vulnerability of adolescents and the amplified burden of those with a rare condition are critical to understanding the challenges they face in the management of their chronic disease. However, it is equally important to acknowledge their potential for cooperativeness.

Adolescence is a critical time in which to form habits and establish health behaviours that optimise adherence. Future support must capitalise on this period in a patient's journey by using an evidence-based and population-specific approach.





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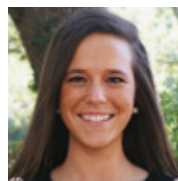
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