Achondroplasia & Adolescence

Supporting well-being in the teenage years



Physical well-being

A practical guide for parents

With insights from parents, achondroplasia advocacy associations, and health experts

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Introduction

Adolescence brings new experiences, responsibilities, and opportunities for independence. For young people with achondroplasia, it can also bring added challenges, from managing fatigue or pain to navigating friendships, body image, social media, and planning for the future.

This is one of a series of guides exploring different aspects of adolescence. It draws on the experiences and insights of parents raising young people with achondroplasia and focuses on typical situations families may encounter.

The guide is designed to be practical, supportive, and grounded in everyday life, offering ideas and suggestions to help families navigate and enjoy this important stage. Each section stands alone, so you can focus on the topics most relevant to you. The ideas shared are based on personal experiences and may not reflect every family's perspective or situation. Parents and adolescents may also see things differently, and sometimes parents may worry more than their teen.

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Disclaimer

This resource is provided for informational purposes only, it is not exhaustive, and is not medical advice and cannot be relied on or take the place of medical advice. Always check with your healthcare team for all healthcare, well-being, or developmental questions or concerns. Every child's needs are unique and considerations presented here may not be relevant in every instance and can vary by country and region.

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How the guide was developed

The guide is an initiative of the BioMarin International Skeletal Conditions Council, which is supported by BioMarin and brings together leaders of patient advocacy associations from around the world. It was developed with input from parents of pre-teens and adolescents with achondroplasia, who shared their reflections, concerns, and practical strategies. Their insights are complemented by advice from health experts who care for young people with achondroplasia.

Meet the BioMarin International Skeletal Conditions Council

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STOWARZYSZENIE NA RZECZ DZIECI ODBLOKUJ ŻYCIE Z ACHONDROPLAZJA

Our thanks to the parents who took part in this project and shared their experiences. Their insights form the heart of this guide.

Meet our expert contributors

We are grateful to the following experts for sharing their clinical perspectives across this project.

Dr Roberta Onesimo
Pediatric Unit - Head
Department of Woman, Child and Public Health
Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome, Italy

Dr Lucrezia Perri
Clinical Psychologist and Psychotherapist
Rare Diseases and Congenital Defects Centre
Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome, Italy

The *Physician's perspective*, *Psychologist's perspective*, and *When to seek professional support* sections in this guide reflect the contributors' clinical experience and professional viewpoints. These sections are intended to provide general educational information – they do not constitute medical advice and should not be relied upon as a substitute for medical advice. Always check with your healthcare team for all healthcare, well-being, or developmental questions or concerns.

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Supporting physical well-being



For teens with achondroplasia, the increased activity levels and growing independence of adolescence bring the excitement of new social experiences but may also lead to a number of physical challenges.[1] Practical strategies can support physical well-being and help young people stay active, included, and engaged.[1]

This guide explores fatigue and pain, participation in sports and activity, nutrition, health monitoring, and how physical health connects with emotional well-being. You'll notice some suggestions are repeated across these topics – that's because some strategies support many areas of physical well-being.

Our son never thinks that he can't do something – only that he might do it in a different way. That's his motto in life.

Parent perspective[2]

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1. Managing fatigue & energy

Sustaining energy levels across the day



Introduction[1]

Adolescence is a time when school, physical activities, and social life all become more demanding, placing new pressures on a teen's energy levels. Many young people with achondroplasia report that they tire more easily compared with peers of average stature, which can make everyday activities like walking with friends or taking part in team sports challenging.

The term 'fatigue' refers to tiring quickly, especially during continuous or peer-paced activity, and it can directly influence participation. Not all children and teens with achondroplasia experience fatigue. Among those who do, it can vary from person to person and be influenced by factors such as physical fitness, levels of regular exercise, and weight. The intensity of fatigue can fluctuate at different times of day and for some people it can be associated with pain.

Parents say encouraging activities where teens can pace themselves and spending time with friends who don't make keeping up an issue are just some of the ways energy levels can be managed – helping teens feel more confident, capable, and able to have fun.

What you may notice[1]

- **Problems keeping up with peers.** Your teen has persistent difficulty matching the pace of the group, for example falling behind on walks or hikes, and tiring early when standing or playing sports.
- **Making adaptations or adjustments to join in.** Some teens accept participating with younger age groups or choosing less demanding activities in order to stay involved.
- **Reduced motivation and participation.** When keeping pace is hard, some teens may be at risk of opting out of activities they value and enjoy, which in turn can affect their mood.
- **After school crashes.** Experiencing periods of low energy that interfere with homework, hobbies, or socializing (beyond what you'd normally expect after a busy school day).
- **Mood changes.** Being irritable or sad after strenuous days.

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Suggestions from parents[1]

The aim isn't to eliminate fatigue but to recognize patterns, reduce unnecessary strain, and build routines that keep teens active in ways that are realistic and socially rewarding. Many young people are very aware of their own physical capacities and do not want to be treated as younger or less capable. They can decide for themselves when a sport or activity doesn't suit them and choose to skip it or ask to try something different. Sometimes, joining activities with younger age groups can be a positive way to stay involved, although it's important teens understand and are comfortable with the reasons, and take part in other activities with peers their own age.

- **Encourage activities where fatigue can be managed.** Prioritize inclusive activities that your teen enjoys or may be keen to try where the pacing can be adjusted to help them succeed. 'Pacing' refers to balancing activity and rest to help manage energy and maintain participation.[3] Because fatigue can vary across the day, encourage young people to listen to their bodies and take breaks when necessary. Parents can help teens recognize early signs of fatigue and decide when to pause or rest. Options like cycling and some styles of dance may allow teens to join in at their own energy level, feel confident in their abilities, and enjoy themselves.

- **Celebrate successful strategies.** Praise aspects such as pacing and effort, not just outcomes like speed or endurance, so that confidence grows from how your teen approaches the activity rather than how they compare with others. Focusing on strengths rather than limitations helps reduce the emotional impact of fatigue.

- **Make the most of supportive peers.** Gently encourage your teen to notice which activities or teams naturally allow for flexible pacing without a negotiation every time. Reassure them that it's okay to take breaks when needed – they just need to let their friends know.

- **Review daily routines and habits.** Sometimes fatigue can be worsened by everyday habits. Take a look at your teen's routines together and consider small changes that may help sustain energy across the day.

- **Plan medical appointments strategically.** Multiple healthcare visits, including physiotherapy, may be tiring for some teens. Where possible, protect the time that's most important to your teen by avoiding clashes with social activities when scheduling appointments.

My daughter feels she must run to keep up with friends, so she gets tired fast.

Parent perspective[1]

The physician's perspective

Understanding and managing fatigue

Fatigue is common in children and adolescents with achondroplasia and can arise from several factors.[4,5] Differences in body proportions and spinal alignment mean everyday movements can require more effort. Ongoing joint or muscle discomfort and reduced muscle endurance may also contribute to tiredness. Sleep-disordered breathing is common in people with achondroplasia, particularly obstructive sleep apnea, a condition in which breathing briefly stops and starts many times when sleeping.[6,7] This can result in reduced sleep quality and excessive daytime tiredness.[6]

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If your teen is experiencing persistent fatigue that interferes with school or daily activities, it's important to get it evaluated. This may include:

- A sleep assessment (polysomnography) by a specialist such as a pulmonologist, especially if the young person has snoring, sleep apnea, restless sleep, or morning headaches.
- Neurologic, orthopedic, and functional assessments to look for other possible causes of fatigue.

Management should be tailored to the young person and their individual needs. Low-impact aerobic activities such as swimming, physiotherapy-guided strengthening programs, maintaining a healthy weight, and good sleep habits can help improve energy levels. Sleep apnea or other identified complications need to be managed by specialists.

The psychologist's perspective

Supporting your teen emotionally

Fatigue in teens with achondroplasia is rarely only physical; it is closely connected to their emotional experience. Daily tasks that take extra effort and activities that require more energy than their peers can become a source of frustration and emotional strain. Young people may feel caught between wanting to participate fully and feeling limited by their energy levels.[4,5]

Caregivers can play an important role in supporting their child – not just in terms of practical assistance, but by listening empathetically, validating feelings of frustration or anxiety, and helping adolescents recognize and build on their strengths. Guiding adolescents to focus on their abilities rather than limitations strengthens motivation and provides a protective buffer against the emotional impact of fatigue.

When to seek professional support

Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Worsening fatigue, such as increased tiredness or difficulty with daily tasks like walking or climbing stairs
- Breathing difficulties during sleep, such as loud snoring or irregular breathing, or waking feeling unrested
- New nervous system symptoms, such as pain or weakness in the arms or legs, or difficulties with balance
- Declining school performance, for example difficulty concentrating, a drop in grades, or loss of interest in school

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2. Managing pain & discomfort

Keeping pain from getting in the way



Introduction[1]

Physical discomfort can become more noticeable during adolescence. Teens may spend more time on their feet with longer school days and busy social lives. Some teens report little or no pain, while others notice activity-related aches or soreness afterwards. Identifying patterns of pain and making small changes can help minimize the problem.

What you may notice[1]

- **Challenges in group activities**. Discomfort may become more noticeable when keeping up with friends, for example on walks.
- **Reduced participation.** Your teen may skip favorite hobbies or choose to join in with younger age groups in order to stay involved.
- **Fatigue alongside pain.** Pain and fatigue often go hand in hand. When discomfort increases, teens may move less, which can affect their fitness and confidence, and, in turn, make being active feel harder.
- **Mood changes.** Pain can have an emotional impact, leading to frustration or avoidance of activities, which can be just as significant as the physical sensation. Irritability, reluctance to go out or mood changes may indicate periods of greater discomfort.
- **Increased interest in health.** Attention to health may rise when pain becomes a problem.

My son will tell me if he has some pain, then we decide if it needs a doctor or if it's just minor.

Parent perspective[1]

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Suggestions from parents[1]

The goal isn't to push through pain, but to make smart adjustments – such as pacing activities and allowing time for recovery – so that your teen's physical goals and social life remain within reach. It's about noticing patterns (when, where, and how long pain lasts), reducing avoidable triggers, and supporting continued participation in activities.

- **Plan routes and settings.** Favor even surfaces, routes with seating, and opportunities for short breaks ('micro-pauses') that fit in naturally with the activity – for example stopping to chat, having a drink, or looking at something together.

- **Tailor sports and activities.** Notice when pain is a problem during sports and be aware that fatigue often comes hand-in-hand with discomfort. Choose ways to participate and session lengths that minimize flare-ups and build in rest periods where possible. Talk through the plan and any adjustments needed with your teen ahead of time so they know what to expect and feel involved in decisions. Many young people recognize their physical capacities and make their own choices about when to step back or try something different. In some cases, joining activities with younger age groups can be a positive way to stay involved, but it's important teens understand and are comfortable with the reasons for doing so, and continue to take part in other activities with peers their own age.

- **Review daily routines and habits.** Sometimes pain can be caused by everyday habits. Take a look at your teen's routines together and consider small changes that may help reduce discomfort, especially for physically demanding tasks. Adaptations and adjustments include alternating between different activities, taking short breaks, and planning for earlier bedtimes if needed.

The physician's perspective

Understanding and managing pain

Pain is common in children and adolescents with achondroplasia, primarily because of how the condition affects the skeleton and muscles.[4,5] Weight-bearing joints, particularly the knees and hips, are often under extra strain, while back pain may result from differences in the alignment of the spine. Muscles can become tired from the way the body compensates through posture, as well as from everyday activities. Some people also experience headaches due to sleep disturbance or spinal compression.[8]

Nearly all young people with achondroplasia experience some form of pain, which is why it is important to regularly ask about discomfort and assess its impact.[5,8] This typically involves a combination of clinical examination, imaging, and an evaluation of how symptoms affect daily life.[9]

Healthcare teams may use questionnaires to help understand a young person's experience of pain, for example the Brief Pain Inventory (BPI) and the Pediatric Quality of Life Inventory (PedsQL).[8,10] This information helps guide a tailored, multidisciplinary approach to managing pain, including physiotherapy to optimize posture and muscle strength, orthotic supports if needed (such as braces or shoe inserts), adjusting activities to reduce the strain on the body, careful use of pain medication when appropriate, and psychological support.

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Pain can influence more than just physical comfort. It can potentially limit a young person's mobility, independence, and ability to take part in social activities, which can reduce their quality of life.[8] For example chronic pain may affect participation in sports and physical activities, reducing independence and making everyday tasks such as walking longer distances more difficult. Persistent back or muscle pain may also lead some young people to avoid social activities, increasing the risk of isolation. Recognizing pain early and understanding its impact can help guide care and ensure young people receive the support they need.[8,9]

The psychologist's perspective

Living with pain

Pain – especially when it recurs over time – is one of the most sensitive issues in the lives of young people with achondroplasia. It's not just a bodily sensation. It can affect mood, self-confidence, motivation to go out, and willingness to join in activities with peers. When supporting a young person with pain, avoid minimizing it ('it's nothing') or dramatizing it ('you won't be able to do anything'). Recognize pain as real and deserving of attention, which may include physiotherapy, medical care, and psychological support. Asking for their views and involving them in decisions helps teens feel like a partner in their own care. It's not just about 'removing pain'. It's about helping your teen live well even when some pain is present, so they can continue building relationships, exploring interests, and planning for the future.

Strategies that may help reduce the impact of pain include:

- **Relaxation and stress-management techniques.** Deep breathing, muscle relaxation, meditation, or visualization can help reduce muscle tension and promote calm.
- **Reframing thoughts about pain.** Help your teen gently challenge negative thoughts, for example replacing 'Pain will stop me from doing everything' with 'I can take a break and continue later' or 'I can adapt the activity so it's more comfortable.'
- **Mindfulness.** Practicing being in the present moment rather than anticipating or worrying about pain can reduce anxiety and improve a sense of control.

When to seek professional support

Sometimes, despite adaptations and day-to-day strategies, pain continues to 'take up too much space' in a young person's life. Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Frequent pain lasting several weeks or months
- Pain interfering with important activities or making your teen become more isolated
- Signs of emotional stress, for example anxiety, sadness or marked irritability
- Frequent need for pain medication, with limited benefit

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3. Sports & physical activity

Maximizing participation and fun



Introduction[1]

Sport and physical activity have a powerful influence on feelings of belonging, confidence, and mood in adolescence. For teens with achondroplasia, the challenge is often the pace and format of sports, rather than willingness to be involved. Many young people can and want to participate, but find peer-paced activities such as team games, long runs, or hikes demand speed and endurance that are hard to match. Parents say the secret is finding ways to keep teens active that are enjoyable, inclusive, and set them up to succeed.

What you may notice[1]

- **Difficulties with the pace and format of activities.** Many adolescents want to participate but struggle to keep up.
- **Joining younger groups.** Sometimes teens accept participating with younger age groups to stay involved. This can work well, but in some situations it may feel like going backwards and affect self-esteem.
- **Negotiating the rules.** Activities that lack inclusivity or require repeated discussions around adjusting the rules are emotionally tiring and can be discouraging.
- **Mood changes after sport.** Participation often lifts mood, while exclusion can contribute to sadness. Avoidance of previously enjoyed sports or low mood after physical activities may occur when teens find the pace or competitive element hard to manage.

Our son's favorite activity is table tennis. He also enjoys riding his scooter, going to the skatepark, and riding his bike.

Parent perspective[2]

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Suggestions from parents[1]

The aim is not simply to do more sport, but to prioritize having fun by choosing the right settings and agreeing on any adaptations up front (so they feel like a normal part of the activity). This approach maximizes both the social and physical benefits of sport. Parents repeatedly underline how inclusive formats and small wins sustain teenagers' engagement with physical activities over time.

- **Encourage activities that motivate.** Choose sports and games where your teen can thrive. Activities that are popular among other people with achondroplasia include table tennis, badminton, adaptive football, swimming, cycling, and freestyle scooter tricks. In some cases, joining activities with younger groups can be a positive way to stay involved, so long as your teen understands and is comfortable with the reasons for doing so, and they continue to take part in other activities with peers their own age. Many young people recognize their physical capacities and make their own choices about when to step back or try something different.

- **Agree adaptations in advance.** Discuss helpful adjustments with teachers or coaches ahead of time so that they are part of the plan.

- **Build progress step-by-step.** Keep sessions short and focus on repeated wins, so bigger goals feel possible over time.

- **Celebrate achievements.** Recognize qualities like effort, skills, and decision-making rather than speed or distance. Track progress against your teen's own goals rather than comparing their results with peers, especially when competition isn't on equal terms. This approach helps build motivation and pride.

- **Connect with the community.** Taking part in activities with others who have achondroplasia or in mixed-ability groups where inclusion is the norm can boost enjoyment and long-term engagement.

- **Protect social time.** Whenever possible, try to schedule care-related appointments outside key sports or social times, so they don't interfere with your teen's routines.

Find something your teen can be good at, maybe scooter riding or Capoeira – it makes them eager to participate.

Parent perspective[1]

Our son likes swimming and going to the pool. He enjoys holding his breath underwater and showing me how long he can last. When he was learning to swim, they used to play games at the end of each class, and he was always the one who could hold his breath the longest. He was very proud of that.

Parent perspective[2]

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The physician's perspective

Physical activity and achondroplasia

Regular physical activity is essential for young people with achondroplasia – it supports muscle strength, aerobic fitness, coordination, and overall well-being.

Certain features of achondroplasia, such as shorter limbs, differences in posture, and reduced muscle strength, can make some forms of exercise more challenging and increase the risk of discomfort and fatigue. Studies show fitness and muscle strength are significantly lower in adolescents with the condition compared to peers of average stature, and many report difficulties taking part in physical activity.[5,11] Low-impact options such as swimming can safely help improve endurance and muscle function. Other physical activities that teens with achondroplasia can successfully take part in include dance, football, and martial arts.

The psychologist's perspective

Building confidence and belonging through sport

Sport is more than just physical exercise. It is a key setting where belonging, comparison with peers, and self-confidence are challenged. When the pace is too fast or the rules are not inclusive, sport can feel like a test instead of a source of fun, fueling anxiety and fear of being judged. Inclusive environments – where pace is adjusted, collaboration is valued, and small successes are recognized – support not only physical health but also self-esteem, body image, and emotional well-being. Experiencing 'I can do this in my way' in a supportive setting helps teens build resilience and a sense of belonging that goes beyond winning or losing. For caregivers, this means the goal is not for teens to do the same as everyone else, but to find forms of participation where they can feel competent, valued, and part of the group.

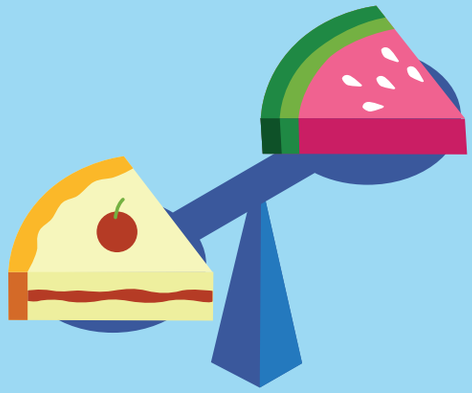
When to seek professional support

Your healthcare team can provide advice and support around safely participating in sport and physical activities. It is important to be aware of not only whether your teen takes part, but also how they feel about these experiences. Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Withdrawal from sports or activities they previously enjoyed for fear of being judged or not keeping up
- Frequent self-critical comments
- Low mood, irritability, or anxiety after physical activity
- Statements about feeling excluded, different, or 'always the one who comes last'

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4. Nutrition & weight



Building healthy eating habits for life

Introduction[1]

Adolescence reshapes appetite, routines, and social life, all of which can change how young people relate to food. For teens with achondroplasia, the enjoyment of eating can collide with fewer opportunities for physical activity. In this context, nutrition isn't about strict rules or perfection. It's about creating predictable, balanced routines that fuel movement, bring pleasure, and avoid framing food as a reward or emotional compensation for life's challenges (a pattern that can sometimes begin in early experiences of food).

A healthy relationship with food matters for all teenagers, and young people with achondroplasia who understand the value of balanced eating can be great role models for their peers, with or without short stature.

What you may notice[1]

- **Imbalance between food and activity.** A love of food, combined with lower physical activity, can affect fitness, energy, and self-image, which in turn may reduce motivation to be active, creating a cycle.
- **Comfort eating.** Your teen may have a tendency to turn to food as a way of coping with low mood.
- **Energy dips.** Noticeable tiredness that reduces motivation for sports practice or activities after school.
- **Reduced confidence.** Changes in body image due to weight gain can have a negative impact on confidence.

Even though my son understands everything about food and health, it doesn't mean it's easy. I'm there with him every day, encouraging, reminding, and supporting.

Parent perspective[1]

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Suggestions from parents[1]

The aim is to keep eating and activity realistic and positive, not a source of pressure or punishment. Family-wide habits, together with physical activities where teens can genuinely succeed and have fun, support motivation, confidence, and healthy routines that last.

- **Embed healthy habits early.** When children grow up with a culture of healthy living from a young age, fitness and nutritious food choices become daily habits.
- **Address weight gain promptly.** Early intervention is important and can help protect both physical health and emotional well-being as your child grows into adolescence.
- **Model positive behaviors.** When parents lead by example in fitness and lifestyle choices, it can help reinforce healthy routines for everyone.
- **Make it a joyful family habit.** Shared routines around shopping, cooking, and walking together make healthy choices feel normal for everyone and prevent teens from feeling singled out.
- **Be there by their side.** Healthy eating isn't always easy at any age. Providing consistent practical and emotional support day-by-day helps young people know their parents recognize their efforts and the extra physical and emotional challenges they face.

Be sporty and healthy as early as possible. People with achondroplasia don't have the same energy, so it's easy for them to put on too much weight.

Parent perspective[1]

The physician's perspective

Nutritional guidance in achondroplasia

People with achondroplasia are at increased risk of becoming overweight or obese from a young age.[12] As children reach adolescence, parents may need to pay closer attention to diet and activity levels to help prevent an imbalance between calorie intake and physical activity.

Achondroplasia has certain metabolic features which mean that the balance of macronutrients within a young person's energy intake may be one of the keys to dietary management.[13] In particular, reducing or avoiding free sugars and choosing complex carbohydrates may be helpful. Prioritizing monounsaturated and polyunsaturated fats (which have protective cardiovascular effects), while reducing saturated and trans or hydrogenated fats, is also advised.[13]

Parents should be aware that standard measures used to diagnose obesity, estimate energy needs, and guide dietary advice may not apply to teens with achondroplasia.[9]

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The psychologist's perspective

Food and body image

Adolescence is a time when young people's relationship with their bodies and with food can become complex. Teens with achondroplasia may face added challenges because having the condition may lead to more frequent comparison with peers. Parents and health professionals can provide practical and emotional support to strengthen self-acceptance, build confidence, and encourage social inclusion. Helping young people develop a positive relationship with their body and food may reduce the likelihood of comfort eating, which can negatively affect self-esteem.

Rather than rushing to solve problems, taking time to listen and understand your teen's emotions is important. Creating a safe space where they can express their concerns without feeling judged or isolated is essential for psychological well-being. Parents can also promote engagement in physical activity by encouraging sports within their teen's abilities, helping set realistic goals, celebrating small successes, and working with teachers or coaches to adapt activities so participation can be positive and inclusive.

When to seek professional support

Your healthcare team can provide advice and support around managing diet, understanding your teen's metabolic requirements, and promoting healthy lifestyle habits. During adolescence, psychological difficulties related to body image are common. Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Difficulty managing weight
- A negative relationship with food, such as comfort eating
- Signs of depression, social anxiety, social withdrawal, or difficulty coping with challenges
- Low energy and declining motivation for physical activity
- Difficulty managing emotions linked to competition or exclusion

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5. Health monitoring & engagement



Supporting positive attitudes and ownership of care

Introduction[1]

Routine medical check-ups and physiotherapy appointments are a part of everyday life for some adolescents with achondroplasia. Most teens go along with this care, but their level of engagement varies – some are more passive, while others accept appointments as routine so long as they don't clash with valued social activities or sports. Engagement is often led by parents and can become a source of friction when care interrupts the things that matter most to teens. Young people tend to be more motivated when care fits their schedule and its purpose is clear. Acceptance can be easier when a parent also has achondroplasia and appointments are simply part of family life.

What you may notice[1]

- **Reactive interest.** Engagement with health may spike when a teen is experiencing pain. This is different from general curiosity without symptoms.
- **Care led by parents.** Encouraging teens to develop independent involvement in healthcare can be a challenge. Parents often handle the logistics, preparation, and take notes during medical appointments.
- **Impact on self-image.** Routine or non-critical appointments like physiotherapy can feel like a time burden to teens and affect their self-image, because they are a reminder of being different from peers.

He's fine with going to the doctor, as long as it's during school hours.

Parent perspective[1]

My son knows I'm on it, so he doesn't worry about it himself.

Parent perspective[1]

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Suggestions from parents[1]

The goal is to normalize care without medicalizing daily life. This may entail protecting key times for socializing and shifting from parental management to shared ownership, and eventually teen-led participation.

- **Protect social time.** Arrange appointments to minimize disruption, for example by coordinating care-related visits on the same day and avoiding times that clash with sports clubs or social activities.
- **Make physiotherapy manageable.** Keep sessions an appropriate length and timed to fit in with daily routines. If something has to give, try swapping a small share of screen time, rather than time with friends.
- **Connect care and activities.** Keep your healthcare team informed of sports activities in school or clubs, and pass their advice on to teachers and coaches so support stays consistent across settings.
- **Encourage teens to take an active role in their healthcare.** Involving your teen in simple tasks such as preparing questions before appointments, tracking symptoms, or deciding what they would like to discuss with their healthcare provider encourages ownership and confidence in managing their own care.

The psychologist's perspective

Supporting engagement in care

Adolescence is a stage of life when identity is being formed. It is important that young people with achondroplasia are active participants in their own healthcare. Regular check-ups and physiotherapy sessions can be both supportive and tiring. If these are viewed mainly as interruptions or reminders of being different, disengagement becomes more likely.

The aim is not to medicalize the teen's life, but to help them develop the feeling of 'I can manage this' when dealing with symptoms and their treatment – listening to their body and taking an active role in their care. Parents can support engagement by gradually shifting care from being entirely adult-led to a shared responsibility and, over time, the responsibility of the teen. When young people are involved in decisions and feel that their point of view is heard, care feels less like an imposition and more like a meaningful part of their life plan.

When to seek professional support

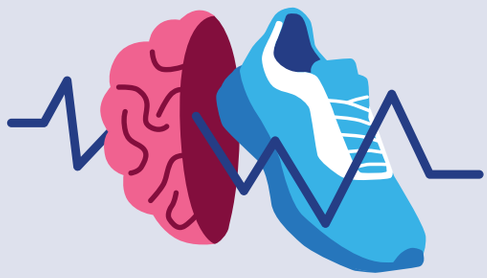
Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Persistent resistance to appointments or physiotherapy, or marked anxiety in advance
- Shame, embarrassment, or reluctance to show or talk about their body
- Ongoing family conflict or tension related to appointments, physiotherapy, or medical care

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6. Physical-emotional link

Protecting mood through participation



Introduction[1]

When physical effort, pace, or access make everyday participation harder, teens may begin to opt out of activities such as physical education, walks with friends, team sports, or social plans. This withdrawal often starts with feelings of sadness, frustration, or embarrassment, and over time can affect self-esteem and relationships. Finding physical activities where teens feel successful and included is a powerful way to protect mood.

What you may notice[1]

- **Participation affects mood.** Being able to participate in physical activities can have an emotional impact. Positive engagement in sports or activities can lift the spirits and help raise self-esteem, motivation, and a sense of belonging. Low mood may follow peer-paced exercise or activities that are difficult to join in.
- **Choosing to stay home.** Some teens may avoid activities due to fear of mockery or standing out.
- **Negative talk.** Physical limitations can be linked to sadness, frustration, and withdrawal. Language may shift from ‘This is tiring’ to ‘I’m not good at this’ or ‘I don’t belong’.

Above all, our son loves his little skateboard and especially his scooter. He likes to ride on the skatepark ramps, and he really enjoys it when we take him there.

Parent perspective[2]

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Suggestions from parents[1]

Challenges exist, and the goal isn't to hide them, but reduce avoidable barriers and help teens take part in ways that feel achievable and socially comfortable.

- **Choose inclusive settings.** Look for environments or situations where adaptations are assumed and the pace can vary. Settings like these encourage success and protect mood and motivation.
- **Acknowledge emotions.** Make space for sadness or anger – emotional responses to physical limitations are normal and valid. Pair this with honest reflections and recognize small wins.
- **Celebrate achievements.** Value qualities like developing skills, good decision-making, and taking part as much as speed or endurance.
- **Protect social time.** Avoid scheduling appointments where they impact on social or sports time and bundle care tasks where possible to minimize disruption to everyday life.

Playing sports with others who have achondroplasia has brought our child joy and confidence.

Parent perspective[1]

The psychologist's perspective

Participation and emotional well-being

Taking part in physical activities is important for the emotional well-being of adolescents with achondroplasia. Like a lot of young people, they benefit from social interaction and being active, but physical challenges may sometimes lead them to withdraw. When young people with achondroplasia feel unable to fully participate, feelings such as sadness and anxiety may arise, which can negatively impact self-esteem.

Psychological growth in adolescence is closely linked to developing skills and feeling part of a group. It is therefore important to encourage participation in physical activities that are adapted to the teen's specific needs but still allow them to build skills and feel that sense of belonging.

Sadness and frustration about physical limitations are normal. A helpful approach is to encourage open conversation about emotions, creating a safe space where the young person can express that they feel unhappy or upset. Emotional growth involves understanding what feels difficult, while also keeping sight of progress and small successes.

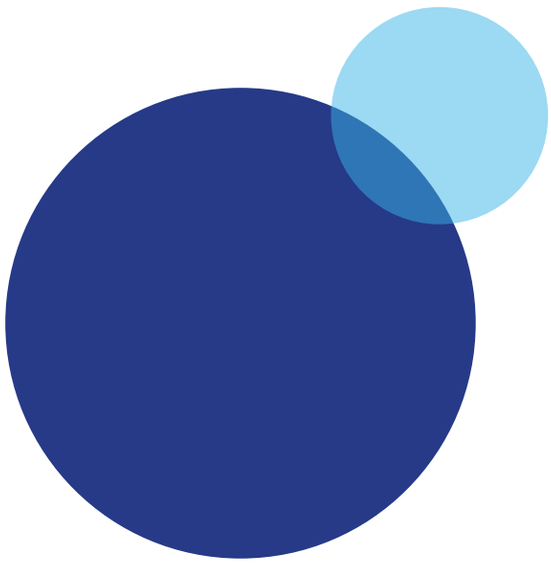
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When to seek professional support

Speak with your healthcare team if you have concerns about your teen's well-being – for example if you notice:

- Ongoing difficulties joining in or withdrawal from physical or social activities because of fear of being judged or a lack of confidence in their abilities
- Low self-esteem
- Signs of significant psychological distress, such as intense social anxiety or depression

If your teen expresses thoughts about harming themselves or not wanting to live, seek urgent medical support. If you believe they are at immediate risk, contact emergency services or go to your nearest hospital emergency department.



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Notes

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