

PARTNERING WITH YOUR CHILD'S SCHOOL TO MANAGE KLS

Given the rarity, episodic nature and variation in presentation of Kleine-Levin Syndrome, it may be difficult for outsiders, including school personnel, to fully understand the impacted child's inability to attend school and/or learn while in an episode. Some may make assumptions or judgements about whether the child is merely lazy, unwilling or faking symptoms to avoid doing work and/or attending school. KLS is not school avoidance but rather an inability to learn or attend school due to the excessive sleep and cognitive impairment during episodes.

Some impacted children/teens may also experience social, emotional or mental health issues separate from, or in response to managing, KLS. Those managing KLS may experience varying degrees of support and cooperation from their child's school. Though caring for your KLSer may be overwhelming and exhausting at times, advocating for them at school is crucial. As a parent or caregiver, what can you do to best support your child and help them lead as normal an academic life as possible?

The below information, considerations and examples may assist you in navigating, communicating and accessing support within U.S. school systems. Though it may be difficult for a variety of reasons, finding a way to partner with your child's school may reduce stress and help your KLSer rebound after episodes. *Please note that the KLS Foundation does not provide legal or educational advice and the information provided is a compilation from a variety of KLSers/caregivers as well as cited sources.

WHAT, WHEN AND HOW TO COMMUNICATE WITH SCHOOLS REGARDING KLS

1. It is important to decide how much information you feel comfortable sharing with your child's school. This may be complicated by the fact that the diagnosis is new and/or symptoms may be unpredictable, inconsistent or atypical. Know that it is your right to disclose, or not, your child's private medical information and that schools have an obligation to protect student privacy under the FERPA act (please read below). That being said, if you choose not to share information, it will be difficult for the school to work with you to put an appropriate plan in place and there may be consequences related to non-attendance.

"The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education". Please consult link for more information on FERPA <https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

2. Once you have decided what information you are comfortable sharing with Teachers, School Nurses, School Counselors, Coaches and/or Administrators, consider how you will communicate that information: in person meeting(s), email, phone call. Below is a sample email sent by a parent to teachers in the first weeks of school:

We hope your first couple of weeks of school are going well! I believe I have spoken with each of you individually but wanted to reach out and make sure you are all aware that our son/daughter has been diagnosed with a very rare neurological condition called, Kleine-Levin Syndrome. His/her symptoms include episodes of excessive sleep (up to 23 hours per day) and cognitive impairment that can last one to two weeks or more. When he/she is experiencing one of these episodes, he/she is unable to attend school or do work at home. When he/she is not in an episode, he/she returns to his/her normal level of functioning. The onset and number of episodes is unpredictable. Sometimes it is over the course of days

that an episode begins. As you may imagine, this is quite disruptive for him/her, though he/she has managed quite well. He/she is a conscientious and capable student outside of these episodes.

Because the syndrome is so rare, there is little information about a cause, treatment or cure (though children eventually outgrow the symptoms in most cases). We are working with doctors at XX Hospital to manage his/her symptoms. We suspect being overtired is a trigger so we are very careful about him/her getting enough rest in between episodes. There may be times when he/she arrives late in an effort to avoid going into an episode or misses days for appointments etc. He/she will likely be out again today, though it is unclear whether this is indeed the start of an episode or not. I will keep you posted.

We are hopeful that he/she will have fewer episodes than last year. Last year, teachers were very gracious in compiling essential work in a folder in the main office. He/she has a 504 Plan and worked with the tutor during the latter half of the school year. We are mindful of the extra demand on your time under these circumstances and are so grateful for your support and understanding! We will do our best to communicate with you regularly about his/her status if he/she is absent.

Like most teenagers, he/she wants nothing more than to be treated like a typical teen and be in school with his/her peers. Please don't hesitate to reach out if you have any questions or concerns.

Thank you for your support,

Parent/Guardian

3. Provide KLS related materials from the KLS Foundation Website and beyond as you deem appropriate.

a. KLS Foundation Brochure <https://klsfoundation.org/wp-content/uploads/2017/12/KLS-Brochure.pdf>

b. KLS Foundation Patient Handout <https://klsfoundation.org/wp-content/uploads/2017/12/KLS-Patient-Handout.pdf>

c. I. Arnulf, J. M. Zeitzer, J. File, N. Farber, E. Mignot; Kleine–Levin syndrome: a systematic review of 186 cases in the literature, *Brain*, Volume 128, Issue 12, 1 December 2005, Pages 2763–2776, <https://doi.org/10.1093/brain/awh620>

d. KLS Foundation compilation of medical publications <https://klsfoundation.org/what-is-kleine-levin-syndrome/kls-medical-publications/>

4. In an effort to help others understand that KLS is more than needing a nap, it may be helpful to provide concrete examples of your child's symptoms (inability to be roused, can't open a tupperware container at age 16, doesn't speak, typically outgoing kid completely withdraws etc) while in an episode. Try to paint a picture of the impact on your child to illustrate that they are not able to do their homework, read or attend school while they are impaired. Additionally, helping others to understand that there may be insomnia or other "softer" symptoms that may take days (and in some cases more time) to resolve before they return to 100%. This may be further complicated if your child's symptoms are outside of the norm as presented in KLS literature (ie. young onset, prolonged episodes, or shorter more frequent episodes, flipped sleep cycles etc).

5. **Provide the school with a letter from your child's doctor that includes: the diagnosis, explanation of symptoms, impact on ability to attend school/learn during episodes, medically excusing absences, recommendations for accommodations.** This letter may trigger an exploration of more formal supports for your child (please see below information on 504 Plans and Special Education).

6. As a caregiver, it can be heartbreaking and discouraging to watch your child missing out on life and school. If you are not feeling supported by the school, it may feel especially discouraging to keep them updated on your child's status. Come up with a plan regarding who you will notify about the onset of an episode as well as how frequently you will keep this point person updated. It can be tricky to predict when fully out of an episode and able to return to school so you may want to keep updates rather vague ("still deep in episode....appears to be improving" etc). Many caregivers have experienced the pain, disappointment and/or embarrassment after indicating that their child is better and will return to school the following day only to have insomnia or re-emergence of symptoms throw a curveball.

7. Remind educators that when your child comes out of an episode, not only are they catching up on school work but they are also making up for lost time with friends, family, work, athletics etc. Helping your child balance all areas of life is important. Ask teachers to imagine what it might feel like to constantly be playing "catch up" in school and life?

8. Ask school personnel what supports are available to students in their building and how they are accessed. Schools have internal systems of support including but not limited to District Accommodation plans, Student Support Teams, School Counseling, tutoring (what is your district's tutoring eligibility requirement? may be eligible after missing XX number of days or if it is *anticipated* that you will miss more than XX number of days), protections and supports for students with disabilities.

9. If you believe your child would benefit from more formal support, you may request a 504 eligibility meeting or Special Education evaluation, at any time and more than once. Both plans may be modified at any point upon recovering of the team. Please see below for more information.

10. Check out these KLS Foundation resources related to school:

- e. Donna Reynolds video from KLS Conference in 2015 about 504 and Special Education <https://klsfoundation.org/idea-and-section-504-education-donna-reynolds/>
- f. Information on Educational Rights <https://klsfoundation.org/educational-rights-for-kls-patients/>

11. Be aware that managing a child's KLS needs in elementary, middle, high school and college may be quite different. Professors at the college level may be subject to certain administrative guidelines and statutes, but can and do exert independent authority over their classes.

KLS-504 and SPECIAL EDUCATION

The above information applies to working with schools informally to meet the needs of your child with KLS. There are a couple of avenues that a student with KLS may access more formal support and protection through public schools if it is determined by the school "team" that they have a disability: 504 Plans and Special Education Services. At any time, a caregiver may

request that their child be evaluated for a 504 or Special Education services (*often a good idea to put this request in writing*). Additionally, schools may initiate the 504 or Special Education evaluation process as they have an obligation to identify children with disabilities. Though governed by different laws, both a 504 and Special Education have processes for determining eligibility, guidelines and for grievances. Your letter of diagnosis and recommendations from your child's medical provider will come in handy in both of these processes. However, evaluations to determine eligibility will go beyond the letter of diagnosis and recommendations from your provider; ultimately, it is you and the school "team" that considers/determines eligibility and subsequently creates the 504-accommodation plan or Special Education Individual Education Plan (IEP). 504s and IEPs may be amended at any point by reconvening the team in the event that circumstances, symptoms or needs change. In both cases, public schools are legally bound to follow established 504s and IEPs. Hopefully the following information will assist you in determining whether you wish to request an evaluation for a 504 or Special Education services.

In practice, there are some basic differences between a 504 and Special Education services/IEP. 504 eligibility is based upon a student having a physical or mental impairment that substantially limits a major life activity as defined in Section 504 regulations at 34 C.F.R. 104.3(j)(2)(ii), (walking, breathing, hearing, speaking, learning, working, performing manual tasks, caring for self, eating, sleeping, standing). During a KLS episode, individuals may be impacted in many of these areas, as well as others. Even in remission KLS may be considered a disability because it substantially limits a life activity when active. Someone found eligible for a 504 may receive *accommodations* (extended time, reduced schedule...please see below for other potential 504 accommodation ideas) to "level the playing field" in order to access their education. There are no associated goals or specialized instructions under a 504 Plan. 504 accommodations may continue into college and protect people with disabilities as adults in their employment if the individual chooses to reveal the disability to their college or employer. The criteria for 504 eligibility is more broad than for Special Education and applies to schools that receive federal funding.

Under the Individuals with Disabilities Act (IDEA) public schools are required to evaluate for Special Education services if requested by the parent/guardian or if they suspect a student may have a disability. A student may be found educationally "disabled" if they meet the criteria in one or more of 13 categories (Specific Learning Disability, Health Impairment, Autism Spectrum Disorder, Emotional Disturbance, Speech and Language Impairment, Visual Impairment, Hearing Impairment, Deafness-blindness, Orthopedic Impairment, Intellectual Impairment, Traumatic Brain Injury, Multiple Disabilities). While in episode, a child is likely impaired in one or more of these categories; outside of episodes, they may not be considered impaired. In addition to meeting one of the 13 categories, the disability must also "adversely affect" their education in order to be found eligible for Special Education services. If found eligible for Special Education Services the student (through age 21) is eligible to receive *specially designed instruction* tied to goals in an Individualized Education Plan (IEP) in order to address the area(s) of disability. <https://sites.ed.gov/idea/about-idea/> Special Education services terminate when the student graduates from high school and/or turns 22 years of age. Please see <https://sites.ed.gov/idea/files/postsecondary-transition-guide-may-2017.pdf> for more information on transitioning beyond Special Education services.

Private schools are not obligated to evaluate or provide Special Education Services (IEP) or 504 accommodations if they do not accept any federal funding. Though not legally bound to honor IEPs or 504s, many private schools do have their own systems in place to help

support students with disabilities, including accommodations. If your child attends a private k-12 institution, you may still make a written request for a Special Education *evaluation* through your local public school. The Public School has a responsibility to evaluate upon caregiver request. Again, if found eligible for Special Education Services through the public school evaluation, the private school is not required to provide the special education supports. Here is a link with more information regarding evaluations and private schools <https://www.understood.org/en/school-learning/choosing-starting-school/finding-right-school/6-things-to-know-about-private-schools-and-special-education>. Though not necessarily legally bound to abide by these plans, you may opt to share IEPs and 504s with the private school if you believe it is in your child's best interest for them to have the information.

Though Special Education Services/IEP terminates at graduation or age 22 (whichever comes first), your child may continue to be eligible for a 504 at college and beyond. "At the postsecondary level the recipient is required to provide students with appropriate academic adjustments and auxiliary aids and services that are necessary to afford an individual with a disability an equal opportunity to participate in a school's program. Recipients are not required to make adjustments or provide aids or services that would result in a fundamental alteration of a recipient's program or impose an undue burden"(<https://www2.ed.gov/about/offices/list/ocr/504faq.html>). A new eligibility meeting and creation of an updated 504 plan specific to college may occur if you choose to share the disability with the college. Colleges and Universities generally have an Office of Disabilities to help support students with disabilities.

Because there is a lot of information shared at both a 504 and Special Education meeting, it may be helpful for you to bring a support person with you to listen, take notes and remind you of your concerns and requests. If financially feasible, some families choose to hire private educational or legal advocates to assist them through this process.

Some potential sticking points in the 504 and/or Special Education process specific to KLS include the reality that your child's participation in the evaluation may be compromised if they are in an episode. Given the excessive sleep, cognitive impairment and processing difficulties, it is not realistic to expect that a child in episode is capable of participating in the evaluation. Speak to your school personnel about how to address this complication because it is directly tied to the disability that is being evaluated. In the event that your child is in episode during the evaluation process, you, your child's medical provider and your child when well, will be valuable sources of information. Additionally, KLS is an impairment that is episodic; outside of episodes, your child may be quite capable academically (this may be a bone of contention regarding special education eligibility as they may not require specially designed instruction outside of episodes and are not capable of receiving specially designed instruction while in episode). Please note that if your child has other disabilities, they may be eligible for additional accommodations or special education services for those as well.

Please check out the below links to learn more about 504s and Special Education:

Frequently Asked Questions about Section 504 and the Education of Children with Disabilities. U.S. Department of Education, Office of Civil Rights (OCR). It's easy to search for specific words/questions in the electronic resource too (Ctrl + F).
<https://www2.ed.gov/about/offices/list/ocr/504faq.html>

Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools <https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf>

Similarities and Differences between Section 504 and IDEA (special education)
<https://files.eric.ed.gov/fulltext/ED427487.pdf>

Differences between Section 504 and IDEA (special education).
<https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans> Video link

POTENTIAL KLS 504 ACCOMMODATIONS

If found eligible for a 504, accommodations will be created and agreed upon by the 504 team. Be prepared to advocate for any accommodations you believe would be useful as the team will discuss reasonable accommodations and come up with a written plan. Please note that there are generally a handful of targeted, reasonable accommodations included in a 504; you may want to think about what accommodations would be most important or relevant in your child's circumstance (this may depend on age, frequency and duration of episodes, other diagnoses etc). Below is a list of potential KLS related accommodations you may want to consider. Please see "Reasonable Accommodations Explained" by the American Psychological Association to learn more <http://www.apa.org/pi/disability/dart/toolkit-three.aspx> about accommodations.

1. There may be situations where KLS prevents him/her from following district attendance policy. In that case, student will be permitted to participate in class, athletics, field trips, school sponsored social events etc. when able. For example, if child is in episode and does not attend school the day of the prom and wakes later in day and is well enough to attend, they will be allowed to do so.

Additionally, if a prolonged absence occurs, and student receives an incomplete grade for the term, student will be allowed to participate in any and all of the above named activities. Allowances in tardy and attendance policies to enable and encourage participation in school and related activities as able (including but not limited to classes, clubs, field trips, athletic participation, school sponsored events etc)

2. Develop health plan with school nurse in the event student feels sleepy, confused or "dreamy": take a nap? Do not initiate questions? Call caregiver? Be specific.
3. If necessary, reduced schedule. (May require more than 4 years to graduate High School).
4. If necessary, altered day (late arrival/early dismissal).
5. Flexibility in assignments and deadlines, including major assessments as needed.
6. Emphasis on mastery of content of work missed during episodes. Reduce/modify homework, classwork, assessments as needed.
7. When possible and appropriate, teachers to provide classwork in advance (weekly syllabus?) so student may work ahead when healthy.

8. Exception from group projects and alternate assignment/assessments provided when in episode.
9. Copy of teacher notes/outlines, study guides or identify peer notetaker during episodes.
10. Plan for communication regarding missed assignments and plan for assessments: Missed assignments to be shared on line? collected in folder in main office and picked up by caregiver for student to use when out of episode?
11. Consideration for outside/online courses to allow for work to be done during episode (more likely during recovery period), between or after episode, or outside of school hours to lighten the academic year workload.
12. Given the recurrent nature of the disorder, student will be provided tutoring in accordance with district policy.
13. Extended time on assessments and/or standardized tests.
14. Provide positive reinforcement; avoid publicly drawing attention to student's absences or missed work.
15. Student will be encouraged to come to class even if classwork or homework is not complete. Follow up plan to be arranged between student and teacher for completion of assignment(s).
16. Administrative Pass may be presented to teacher, followed by student arrival at nurse or main office (is escort needed?) to access appropriate support personnel.
17. Breaks as needed during classwork and assessments.

Caregivers responsibility:

18. Define communication-daily? weekly? communication between home and school to notify/update regarding episodes and related issues.
19. Provide documentation and information regarding KLS.

REFERENCES

KLS Foundation website. <https://klsfoundation.org/>

Reasonable Accommodations Explained. American Psychological Association.
<http://www.apa.org/pi/disability/dart/toolkit-three.aspx>

Section 504 and IDEA: Basic Similarities and Differences S. James Rosenfeld, Esq. President EDLAW, Inc. 1996. <https://files.eric.ed.gov/fulltext/ED427487.pdf>

Understood for Learning and Attentional Issues. <https://www.understood.org/en>

U.S. Department of Education, Family Educational Rights and Privacy Act.
<https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

U.S. Department of Education, Individuals with Disabilities Education Act.

U.S. Department of Education, Office for Civil Rights.

U.S. Department of Education, Office for Civil Rights, Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools (December 2016).

U.S. Department of Education (Department), Office of Special Education and Rehabilitative Services, A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, Washington, D.C., 2017.

