School Healthcare Professional Support for Student Transition from Pediatric to Adult Care

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American College of Rheumatology
Empowering Rheumatology Professionals

the lupus initiative
Eliminating Health Disparities in Lupus

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Fact Sheet for the School Healthcare Provider Regarding Student Transition of Care from Pediatric to Adult Care

Importance of Smooth Transition:

- A well-planned transition from family- or home-based care to independent self-management can be challenging for students.
- Many pediatric rheumatologists have policies or guidelines to support teens and young adults in their transition to adult care.
- Students with childhood-onset lupus are at higher risk for complications and mortality compared to those with adult onset lupus.
- By understanding the preparations necessary for a successful transition of care, the school healthcare professional can be an asset during this process.

Differences Between Adult and Pediatric Clinic Visits:

- When compared with pediatric visits, adult clinic visits are often significantly shorter, with a longer duration between office visits.
- There is an expectation for the teen or young adult, rather than the caregiver to relay information to the healthcare provider.
- More responsibility for appointment scheduling will be placed on the teen or young adult than compared to pediatric clinics, and fewer accommodations are made for late or no-show appointments.

Setting a Strong Foundation: Role of the School Healthcare Professional Support

- The school healthcare professional can support the anticipated transition of a student from family supported to independent self-management in coordination with the student's caregiver(s) and/or physician in the student's early teens. This tool is designed for use by the school healthcare professional to support a seamless transition.
- Identify and address professional development and competency needs related to the management and treatment of childhood-onset systemic lupus erythematosus (cSLE).
- Obtain consent required to share information among the student, caregiver, school, and healthcare professionals.
- Facilitate communication and collaboration among the student, caregiver, healthcare providers.
- Using the nursing process, collaborate with the student and caregiver while identifying, assessing, and planning for the transition needs of the student with lupus.
- Meet periodically with the caregiver and student to develop goals for student self-management and transition.
- Develop a Transition Plan in collaboration with the student and caregiver.
- Include the following into the transition plan:
  - resources to support successful pediatric to adult care transition
  - education to address gaps and improve student self-management of lupus
  - anticipatory guidance related to young adulthood development changes
  - strategies to enhance coping and stress management

Setting a Strong Foundation: Role of the School Healthcare Professional Support (cont.)

- Foster the gradual development of independent self-management:
  - ask the student about their medication regimen rather than defaulting to the caregiver
  - support the student to take ownership of the medication schedule at school, rather than relying on prompts
  - ask the student if they know the medication dose and why they take it, to promote greater understanding of their health
- Advocate for the development of school or district policies that address transition planning as part of school health services.
- Ask students about changes to their medical care.

Student Skills Needed for Success:

- Young adults will need to be able to:
  - fill prescriptions independently
  - adhere to medication regimen without prompting from family
  - schedule medical appointments
  - recognize and respond appropriately to problems between appointments
- Students with cSLE may additionally need to understand:
  - where to go for infusions, and how to set up those appointments, as these may not be performed in the regular office
  - how/where to get labs and imaging studies done when required
  - how to communicate with their team of healthcare professionals and keep all informed and up to date

Health Insurance:

- Insurance plays a critical role in disease management and represents another area where the school healthcare provider can initiate supportive conversations.
- Lapses in insurance frequently cause large interruptions in patient care, with decreased access to specialists, inability to get necessary lab work done and inability to pay for medications.
- A discontinuation of insurance coverage contributes to disease flares, hospitalizations and worse outcomes.
- As students become young adults, this is a time when they are often forced to determine their own insurance coverage and may no longer rely on their caregiver(s).
- Although obtaining insurance is not the responsibility of the school healthcare professional, the school healthcare professional can encourage students to consider coverage after graduation.

Ensuring Student Knowledge About Lupus:

- To ensure students can manage their disease independently, they need knowledge and understanding of:
  - what cSLE is, how it has clinically affected them, and what medications they must take for it
  - what other specialists they see regularly
  - how often they require monitoring labs, and any drug allergies or adverse medication reactions they have experienced
- School healthcare professionals can check if students understand this information by asking them about it.
  - in younger children, start with questions about what their illness is and what symptoms it has caused
  - as students progress through high school, the school healthcare professional may ask more detailed questions. Editable forms that can be updated over time may be helpful for tracking this information and monitoring progress

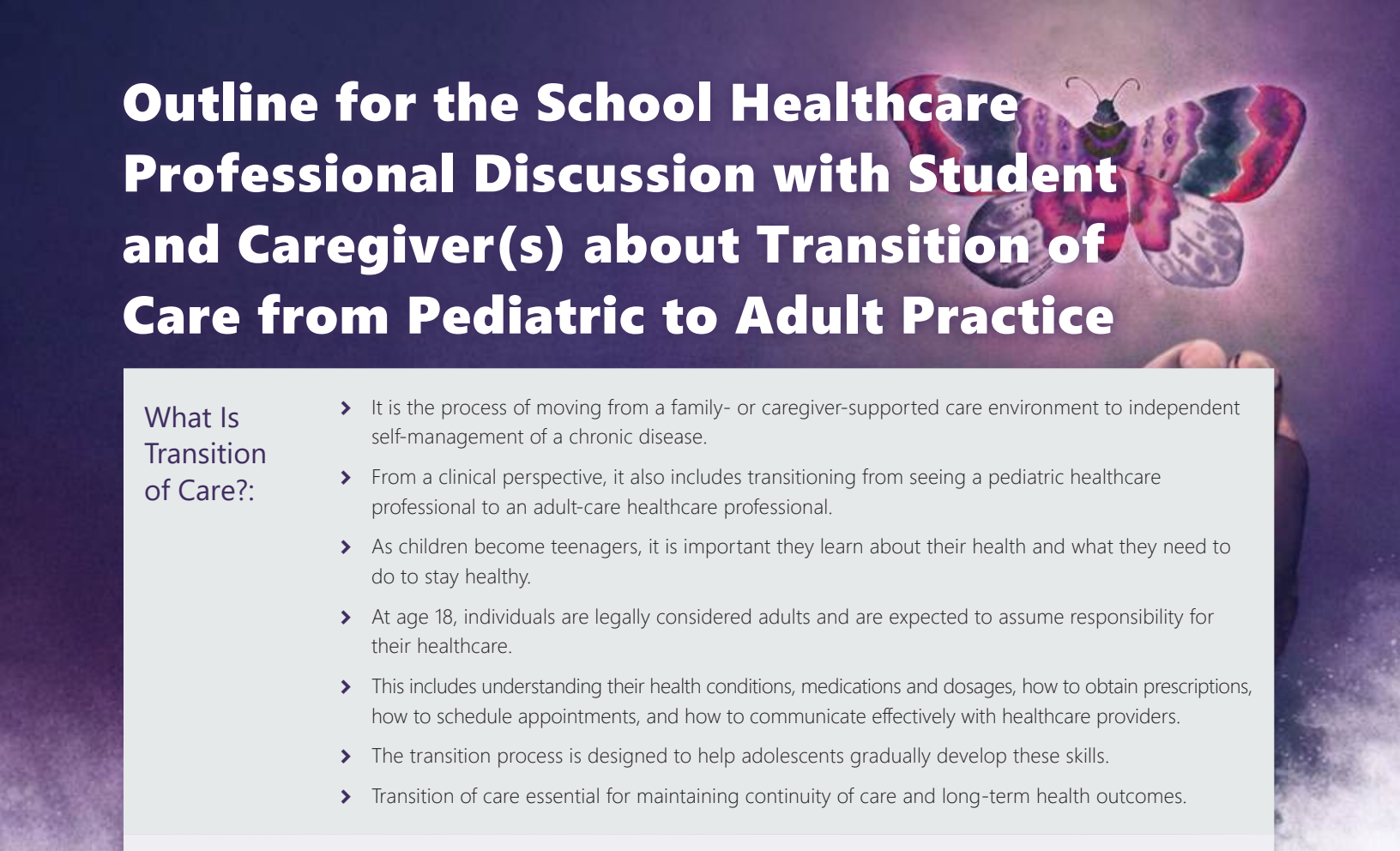
Six Core Elements of Transition Care from Pediatric Care to Adult Care Timeline and Checklist for the School Healthcare Professional

Practice	Age	Activity	Actor	Timing
1. Transition Planning	12 to 14	Assist student and family to complete attached transition plan and discuss with them in the family's preparation for discussions with student's physicians Note: this activity is not intended to replace any clinical transition of care policy in effect in an individual doctors' office	School healthcare professional	Annually at the beginning of each school year.
2. Tracking and monitoring	14 to 18	Track the progress of youth and their cargivers in their preparation of transitioning through annual updates of the Student Transition Readiness Assessment	School healthcare professional Student Caregiver(s)	Annually at the beginning of each school year, but could also be updated during the year if changes occur in the disease course
3. Transition readiness and orientation to adult practice	14 to 18	Conduct transition readiness assessments with the student and/or caregiver	School healthcare professional Student Caregiver(s)	Annually
4. Transition planning and/or integration into adult approach to care or practice	14 to 18	Provide copies of student's transition plan to student and caregiver, which may be used to support/facilitate the student's physician in the implementation of a clinical transition policy	School healthcare professional Student Caregiver(s)	Annual updates
Steps 5 and 6 will be handled by the pediatric rheumatologist.				
5. Implementation of physician's transfer of care policy and/or initial visit	18 to 21	Transfer of care with information and communication including residual pediatric clinician's responsibility	Student Caregiver(s) Pediatric Practitioner Adult Practitioner	Update as needed
6. Transition completion/ ongoing care	18 to 26	Young adult has been seen by the new clinician and reviewed most recent readiness assessment	Student Adult Practitioner	Update as needed

Patience H. White, MD, MA, FAAP, FACP, a W. Carl Cooley, MD, FAAP, Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, America Academy of Pediatrics, PEDIATRICS Volume 142, number 5, November 2018:e20182587

GotTransition.org

Outline for the School Healthcare Professional Discussion with Student and Caregiver(s) about Transition of Care from Pediatric to Adult Practice



What Is Transition of Care?:

- It is the process of moving from a family- or caregiver-supported care environment to independent self-management of a chronic disease.
- From a clinical perspective, it also includes transitioning from seeing a pediatric healthcare professional to an adult-care healthcare professional.
- As children become teenagers, it is important they learn about their health and what they need to do to stay healthy.
- At age 18, individuals are legally considered adults and are expected to assume responsibility for their healthcare.
- This includes understanding their health conditions, medications and dosages, how to obtain prescriptions, how to schedule appointments, and how to communicate effectively with healthcare providers.
- The transition process is designed to help adolescents gradually develop these skills.
- Transition of care essential for maintaining continuity of care and long-term health outcomes.

Why it is important to prepare for transition:

- Regular medical visits are necessary to monitor health status, manage chronic conditions, and address acute concerns. healthcare professionals can take better care of patients when people understand their health, keep their appointments, and don't go long periods of time without seeing a healthcare professional.
- This represents significant responsibility for a young adult; proactive planning helps ease this transition. In a student with cSLE and other medical problems, it is even more important that this process goes smoothly.
- Since people with cSLE usually need to take medications, gaps in healthcare professionals' visits may mean they do not get their medications, which may lead to disease flares, missed school or work, and, in some cases, hospitalization.
- To prevent these outcomes, patients, caregivers and healthcare professionals should collaborate to facilitate a transition that allows young adults to take on these responsibilities.

How can we prepare for it:

- Planning for transition to an adult-care healthcare professional should begin in early adolescence. A transition policy should be available from the healthcare provider's office to notify patients and caregivers of the age at which the student will be expected to change to an adult healthcare professional.
- As adolescents mature, they should gradually assume greater responsibility during clinic visits, including communicating directly with healthcare professionals and understanding their medications.
- This packet was developed to document the student's medical history, lupus management, and practical healthcare responsibilities. It can be filled out starting at the beginning of high school in collaboration with the school healthcare professional. At the beginning, caregiver(s) and healthcare professionals may need to help to answer the questions.
- The goal is that by the end of high school, the student can independently complete the form and demonstrate understanding of its contents.

Student Transition Readiness Assessment

Beginning in high school, the Student Transition Readiness Assessment should be reviewed and updated annually at the beginning of each school year, in collaboration with the school healthcare professional. The student and/or caregiver may find it useful to continue regular updates following high school graduation.

Student Name: _____ Date of Birth: _____ / _____ / _____ Today's Date _____ / _____ / _____

(MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Families: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level.

☐ **Check here** if you are a family member completing this form.

	No, I do not know how	**No,** but I want to learn	**No,** but I am learning to do this	**Yes,** I have started doing this	**Yes,** I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?	☐	☐	☐	☐	☐
2. Do you know what to do if you are having a bad reaction to your medications?	☐	☐	☐	☐	☐
3. Do you take medications correctly and on your own?	☐	☐	☐	☐	☐
4. Do you reorder medications before they run out?	☐	☐	☐	☐	☐
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?	☐	☐	☐	☐	☐
6. Do you follow-up on any referral for tests, check-ups or labs?	☐	☐	☐	☐	☐
7. Do you arrange for your ride to medical appointments?	☐	☐	☐	☐	☐
8. Do you call the doctor about unusual changes in your health (For example: allergic reactions)?	☐	☐	☐	☐	☐
9. Do you apply for health insurance if you lose your current coverage	☐	☐	☐	☐	☐
10. Do you know what your health insurance covers?	☐	☐	☐	☐	☐
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?	☐	☐	☐	☐	☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?	☐	☐	☐	☐	☐
13. Do you keep a calendar or list of medical and other appointments?	☐	☐	☐	☐	☐
14. Do you make a list of questions before the doctor's visit?	☐	☐	☐	☐	☐
15. Do you get financial help with school or work?	☐	☐	☐	☐	☐
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?at you are feeling?	☐	☐	☐	☐	☐
17. Do you answer questions that are asked by the doctor, nurse or clinic staff?	☐	☐	☐	☐	☐
Managing Daily Activities					
18. Do you help plan or prepare meals/food?	☐	☐	☐	☐	☐
19. Do you keep home/room clean or clean-up after meals?	☐	☐	☐	☐	☐
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?	☐	☐	☐	☐	☐

These resources are available to school healthcare professionals and families to assist their student in preparing and practicing taking care of their medical needs throughout their high school career.

- https://selfcare.thelupusinitiative.org
- https://www.lupus.org/resources/lupus-at-school-aguide- for-parents-and-kids
- https://www.lupus.org/resources/assistance-atschool-for-children-with-lupus
- www.rheumatology.org/pediatric-to-adult-rheumatology-care-transition
- GotTransition.org
- https://learn.nasn.org/courses/76543
- www.nasn.org/nasn/advocacy/professional-practice-documents/position-statements

USE OF PROFESSIONAL JUDGMENT: This activity, including all educational links, is intended to be used as a tool to assess the base knowledge of the learner. The information presented relates to basic principles of diagnosis and therapy, and is meant in no way to substitute for an individual patient assessment based upon the healthcare provider's examination of the patient and consideration of laboratory data and other factors unique to the patient.

Student Transition Plan

The Student Transition Plan can be completed by the student and their school healthcare professional, and copies should be provided to the student and their caregiver(s). Once completed, the student should continually update the Information Sheet and share with any new health care professional.

My history with cSLE: (How it has affected me/what symptoms it causes)

My initial diagnosis was when I was _____ years old

Hospitalizations

Hospitalizations Due to cSLE	
Age	Reason for Hospitalization

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Medications

Current Medications

Current Medication	Dose	Current Medication	Dose

Medications I Should Avoid

Medication Name	Reason (allergy, adverse reaction, could cause lupus flare)

Medications I Am Not Currently Taking

Medication Name	Reason I'm No Longer Taking (cost, side effect, ineffective, etc.)

Health Care Professionals

Pediatric Rheumatologist	
Name of Pediatric Rheumatologist	
Office Contact Number	
Office Address	

Adult Rheumatologist	
Name of Adult Rheumatologist	
Office Contact Number	
Office Address	

Local Physician (if going to college, etc.)	
Name of Local Physician	
Office Contact Number	
Office Address	

Other Specialists	
Specialty	Name of Specialist

How do I contact my rheumatologist during the week (office hours)?

How do I contact my rheumatologist after hours/weekend?

What should I do if I have an urgent situation? (on call doctor? ER? Primary care doctor? Urgent care? Student Health Center? Etc.)

How do I contact my other healthcare professionals to give updates if my condition changes?

Health Care Professionals

Where do I get my blood work (labs) done?

Home Lab:

Out of Town/College Lab:

Where do I get imaging (X-rays/CTs/MRI) done?

Where do I get other studies (PFTs) done?

Pharmacies					
	Local	24 Hour	Out of Town/ College	Specialty	Mail Order
Name					
Phone Number					
Address					

Appointments, Transportation and Insurance

How do I get to my appointments?

What is my back-up plan for transportation if my normal transportation is not available?
(Bus? taxi? friend/family? Rideshare service such as Uber or Lyft?)

What insurance do I currently have?

When will it expire?

Support System

Do I require any accommodations to help me succeed in school/work/etc. while living with cSLE?

If so, what are they? (E.g., Extra time to get to class? Limitations to credit hours? Needing to live in close proximity to my classes? Limitation on extracurricular activities due to fatigue?)

Are there support groups available to me if needed?

If yes, are the support groups online, in person, home, or at college?