

Guidance to Independent Self-Care for Students with Lupus



AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



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School Healthcare Provider Support in Student Transition to Independent Self-Care and from Pediatric to Adult Care

Fact Sheet for School Healthcare Provider Regarding Transition of Care from Pediatrics to Adult Practice

Importance of Smooth Transition:

- A well-planned transition from care and support provided primarily in a family or home setting to independent self-management away from that family support may be difficult for a student.
- The advance planning support provided in this packet may support the policy of the current pediatric rheumatologist to an adult health care provider, which is a crucial component of medical care for teens and young adults.
- When compared with adult patients, pediatric lupus patients are at risk for higher rates of complications and mortality from their disease.
- By understanding the preparations necessary for a successful transition of care, school healthcare providers can be assets during this process.

Setting a Strong Foundation: Role of the School healthcare provider

- The school healthcare provider may support the anticipated transition of a student from family support 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 provider to facilitate a seamless transition.
- From a clinical perspective, the actual policy of transition of care from the student's pediatric rheumatologist to an adult rheumatologist may be addressed separately by the patient's physician in coordination with the patient and caregiver(s).
- The Transition of Care Plan will inform caregiver(s) and students on
 - » When the student may be expected to transition to an adult provider
 - » Upcoming changes in medical decision making and responsibility that occur as the patient ages into the adult system.
 - » Resources and planning for successful, independent self-management.
- While these changes will mostly take place outside of the school setting, school healthcare providers can assist patients during this process by encouraging graduated autonomy in their interactions with students and asking students about changes to their medical care.

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 patient rather than the caregiver to relay information to the doctor.
- More responsibility for appointment scheduling will be placed on the patient than compared to pediatric clinics, and fewer accommodations are made for late or no-show appointments.
- School healthcare providers and caregiver(s) can help prepare students for these changes by helping them develop independent managing skills like:
 - » speak directly to the physician at office visits
 - » update school healthcare providers, under caregiver(s) supervision, on any changes that need to occur to their care plan/medications, as well as be the one initiating taking regular doses of medications.

Patient Skills Needed for Success:

- Young adult patients will need to be able to:
 - » fill prescriptions
 - » adhere to medication regimens without caregiver(s) prompting
 - » learn to schedule appointments
 - » know what to do if they have a problem between appointments
- School healthcare providers can help facilitate acquisition of these skills by:
 - » inquiring about a student's medication regimen to the student themselves, rather than defaulting to the caregiver(s)
 - » in situations where a student must receive medications at school, encourage the student to take ownership of the medication schedule, rather than relying on prompting
 - » asking the student if they know the dose of the medication and why they take it an effort to stimulate greater understanding of the student's own health.
- More specific to SLE than other chronic diseases, a student may also need to know:
 - » 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 providers and keep all informed and up to date
- Although these requirements occur outside both the office and school settings, it is helpful for school healthcare providers to know of this component of disease management.

Health Insurance:

- Insurance plays an important role in disease management and provides another area in which school healthcare providers can help stimulate conversation.
- 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).
- While it is not the responsibility of a school healthcare provider to assist a student with obtaining insurance, a school healthcare provider can ask whether a student has considered insurance coverage after graduation/turning 18. This will create an additional safety check to decrease chances of lapses in coverage. If needed, students can/should be referred to community resources for assistance in determining options.

Ensuring Patient Knowledge About Lupus:

- To assure students will be able to care for their disease by themselves, students need knowledge and understanding of
 - » what lupus 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 providers 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 nurse may ask more detailed questions.
 - » Forms that can be edited over time can be helpful for tracking this information.

Six Core Elements of Transitioning Care from Pediatric Care to Adult Care Timeline and Checklist for School healthcare provider

Practice	Age	Activity	Actor	Timing
1. Transition Planning	12 to 14	Assist student and caregiver(s) to complete attached transition plan and discuss with student and family 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 provider	Annually at the beginning of each school year.
2. Tracking and monitoring	14 to 18	Track progress of youth and/or family transition preparation through annual updates of the Student Transition Readiness Assessment	School healthcare provider 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 youth and/or family	School healthcare provider 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 family, which may be used to support/facilitate the student's physician in the implementation of a clinical transition policy	School healthcare provider Student Caregiver(s)	Annual updates
<i>Steps 5 and 6 will be handled by the pediatric rheumatologist.</i>				
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

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

What Is Transition of Care?:

- Transition of care is the process of moving from a care environment supported by family or other caregivers, to independent self-management of a chronic disease.
- From a clinical perspective, it also includes changing from seeing a doctor that treats only children to a doctor who treats adults.
- As children become teenagers, it is important they learn about their health and what they need to do to stay healthy.
- When teenagers turn 18, they are considered an adult and will need to care for themselves. This includes knowing about any health problems, knowing what medications they take, where to get medications, how to schedule appointments and how to speak with their doctors, among other tasks.
- The transition process is created to help teenagers learn how to do all of these things.

Why it is important to prepare for transition:

- Transition of care is important for everyone. In order to stay healthy, people need to see doctors regularly to check that there is nothing wrong and get treatment when they are sick. Doctors 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 doctor.
- This is a lot of responsibility for a young adult, so planning for this transition makes it easier. In a student with lupus and other medical problems, it is even more important that this process goes smoothly.
- Since people with lupus usually need to take medications, gaps in doctors' visits may mean they do not get their medications, which may make their lupus flare up, causing them to feel unwell, have to miss school or work, and sometimes, even wind up in the hospital.
- To avoid this, patients, caregiver(s), doctors, nurses and social workers should work together to facilitate a transition that allows teenagers to take on these responsibilities.

How can we prepare for it:

- Planning for the transition to a doctor who treats adults should start in a patient's early teens. A transition policy should be available from the doctor's office to notify patients and caregivers of the age at which the student will be expected to change to an adult provider.
- As teenagers become young adults, they should be given more responsibility to talk to the doctor at clinic visits, learn their medications and learn what other things are required for them to take good care of themselves.
- To help with this process, we have created this packet that helps to outline the student's history with lupus and how their lupus has been treated, as well as practical considerations such as how to set up their appointments, etc.
- Please start working on filling out this information at the beginning of high school in collaboration with the school healthcare provider. At the beginning, caregiver(s) and doctors may need to help to answer the questions. The goal is that by the end of high school, the entire form is completed, and the student understands all of the information on the form.

Student Transition Readiness Assessment

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

Patient 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 Caregivers: 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 caregiver completing this form.

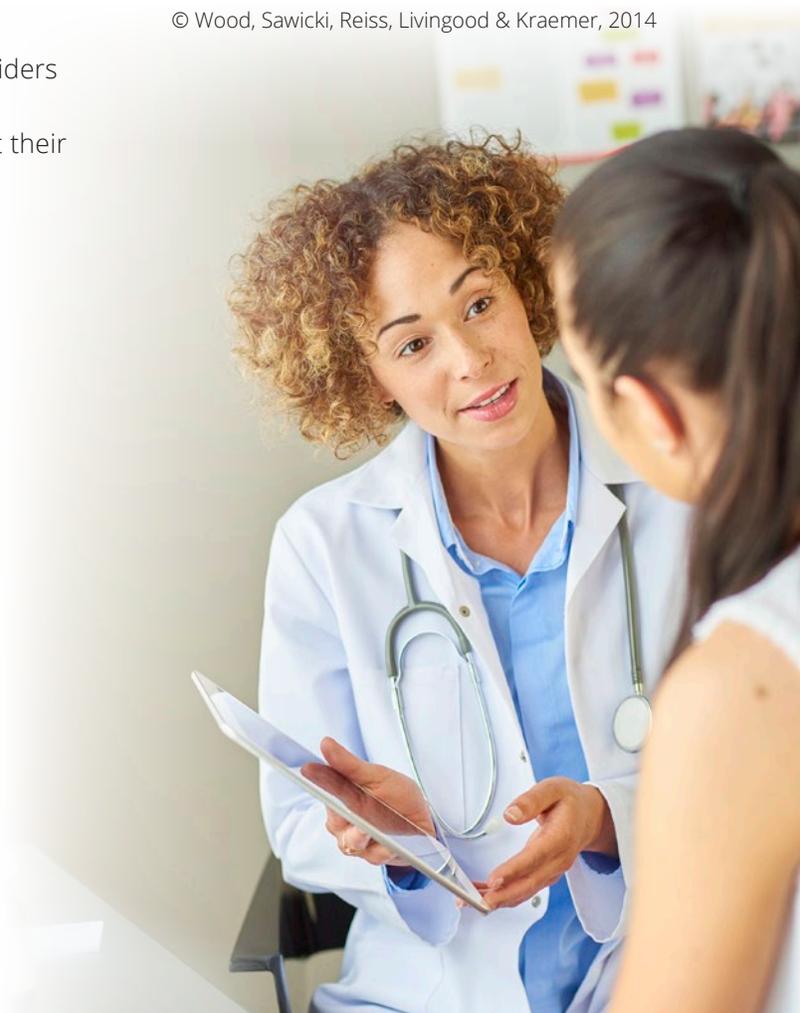
	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input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

	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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you keep a calendar or list of medical and other appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you make a list of questions before the doctor's visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you get financial help with school or work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing Daily Activities					
18. Do you help plan or prepare meals/food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you keep home/room clean or clean-up after meals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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These resources are available to school healthcare providers and caregiver(s) to assist their student in preparing and practicing taking care of their medical needs throughout their high school career.

- > <https://selfcare.thelupusinitiative.org>
- > www.usinlupus.com/pdf/lupuschecklist.pdf
- > www.usinlupus.com/pdf/appointmentprepguide.pdf
- > www.usinlupus.com/pdf/lupusimpacttracker.pdf
- > www.usinlupus.com/tools/mylupuslog.html
- > www.talksle.com/pdfs/lupus-journey-action-plan.pdf
- > www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition
- > GotTransition.org



Student Transition Plan Patient Information Sheet

The Student Transition Plan should be completed by the student and their school healthcare provider, 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 provider.

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

My initial diagnosis was when I was _____ years old

Hospitalizations

Hospitalizations Due to Lupus

Age	Reason for Hospitalization

Medications

Hospitalizations Due to Lupus

Current Medication	Dose	Current Medication	Dose

Medications I Should Avoid

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

Medications I Should Avoid

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

Health Care Providers

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

Provider Name

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 providers to give updates if my condition changes?

Health Care Providers

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 lupus?

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?

Online? In person? Home? At college?
