Recommended Approach for Transitioning into Adult Practice

Turner Syndrome

Background for Transition Visits

- A team approach within the practice is recommended. Be sure that staff understands special situation of transition of care.
- The patient is not yet fully initiated into the “adult model” and may require assistance and support.
- Parents should be allowed to attend appointments if patient desires. It is recommended that the patient complete a visitor information form to inform new provider who, if anyone, can attend appointments. Consider asking the patient to sign a form allowing the healthcare team to communicate with the patient’s parents.
- Extra consideration in scheduling and confirming the appointment may be necessary.
- The patient may also need assistance with:
  - The “unknown” of new facility (directions, parking issues).
  - Insurance issues.
  - Expectations for what to bring to appointment
    - Insurance card
    - Paperwork from former pediatric endocrinologist
    - Forms for the new physician (online, mailed)
    - List of medications or prescription bottles
  - The new healthcare team should greet the patient with the awareness that she is transferring care and provide support and assistance with the check-in process and paperwork.
    - Confirm contact information for the patient; ask about preferred name and how she prefers to be contacted (cell phone, text, email, depending on practice situation).
    - Consider developing “Welcome to the Practice” guide that would provide this information to your new patient.

The First Encounter: Allow Ample Time

- Review HIPAA and determine if parents/others are permitted to receive/hear information about the transitioning young adult.
- Review contact information during office hours and for evenings/weekends in case questions arise.
- Review clinical summary with patient or if patient transitioning without a summary from prior physician, cover items on the clinical summary during history process.
- Pay special attention to concerns about body image, reproductive issues, learning disabilities, fears, coping, family stressors.
- Ask about any concerns or questions
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- Ask about participation in Turner support network. Consider referral to local group if patient is not already participating.
- Review other conditions or issues associated with Turner Syndrome. Identify the primary care physician or the specialist who will have primary responsibility for handling each concern.
  - Fertility and family planning.
  - Hormone Replacement Therapy
  - Cardiovascular disease, hypertension.
  - Hypothyroidism
  - Celiac Disease
  - Depression, anxiety, and low-self esteem
  - Metabolic Syndrome, Diabetes risk.
  - Liver function.
  - Audiology evaluation.
  - Metabolic bone disease.
  - Exercise/Fitness/Weight control.
  - Learning Disabilities.
  - If there are multiple risk factors for aortic dissection, consider a wallet card or bracelet to alert medical personnel.

Ongoing Monitoring¹

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>Cardiology Evaluation (MRI, EKG)</td>
<td>At baseline, prior to pregnancy planning, every 5-10 years as indicated.</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>Annually</td>
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<tr>
<td>ENT and Audiology</td>
<td>Every 1-5 yr</td>
</tr>
<tr>
<td>Fasting glucose, A1C, lipids, cbc, BUN/creatinine, vitamin D</td>
<td>Annually</td>
</tr>
<tr>
<td>DEXA scan</td>
<td>At initial visit and then as indicated</td>
</tr>
<tr>
<td>Liver and thyroid screening</td>
<td>Annually</td>
</tr>
<tr>
<td>Celiac Disease Screen</td>
<td>As indicated</td>
</tr>
<tr>
<td>Psychosocial Evaluation</td>
<td>As indicated</td>
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</tbody>
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- Discuss care plan for ongoing follow up:
  - Discuss/provide a Turner Syndrome Fact Sheet from the Turner Syndrome Society (http://turnersyndrome.org/learn-about-ts/fact-sheet)

or from the Hormone Health Network (http://www.hormone.org/questions-and-answers/2011/turner-syndrome) on recommended testing and follow-up. Review what is needed now and what the plan will be for ongoing/future visits.

- Discuss expectations of how an ‘adult’ clinic will work in the future (how the patient can get the most out of the visit).
- Discuss how to handle interim questions – Crisis and Non-urgent (When do you want the patient to call? With whom should they speak (nurse, MD)? What is the best way to communicate?
- Let patient know if there is a specific urgent care/ER/hospital in which the physician works and assess if it is covered by the patient’s insurance.
- Assess need for/willingness for any additional education.