

Turner Syndrome

Developed by:

Endocrine Society

Hormone Health Network

Turner Syndrome Foundation

How Developed: Chronic endocrine conditions like Turner Syndrome can be complex and challenging for patients to successfully manage—and especially when transitioning to a new health care team. Recognizing the need to improve this transition process and to enhance care coordination between practices, the Endocrine Society spearheaded an initiative to develop pediatric-to-adult transitions of care tools for a variety of endocrine conditions. Partnering with a broad coalition of stakeholder organizations, condition-specific working groups were established with experts in the field to evaluate gaps in care coordination and to begin addressing needs in these areas. The resulting toolkits provide a comprehensive approach to successfully managing transitions for patients with various endocrine conditions.

Tool Name	Description of Tool	How to Use Tool
Provider Assessment of Patient Skill Set	An assessment tool intended to be utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.	This form is suggested to help assess the teen/emerging young adult’s knowledge and skills regarding Turner Syndrome and its management. The tool is intended as an aide to help assess the readiness of older teens/emerging young adults in the transition and to be transferred from pediatric to adult care providers.

<u>Transition Readiness Assessment</u>	An assessment tool to be utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).	Adult care team should direct the patient to consider the statements in the patient self-assessment <u>tool</u> and note how important it would be to discuss the item with your healthcare team as you are moving on from pediatric to adult diabetes care.
<u>Clinical Summary & Transfer Record</u>	A medical record summary that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult practice.	The clinical summary/transfer record <u>form</u> should be completed, signed, and dated on last page by referring provider and patient. Patient and family to review and give completed form to new adult health care provider.
<u>Dosing Standards for Estrogen</u>	This guide provides an overview of dosing strategies for patients with Turner Syndrome.	This <u>guide</u> should be used by the pediatric and adult providers to gain a better understanding of how dosing changes throughout the transition period.
<u>Recommended Approach for Transitioning into Adult Practice</u>	This resource serves as a receiving guideline for the adult provider and includes information on how to begin the final phase of the transition.	This <u>recommended approach</u> is intended for adult care practices as they plan for receiving emerging adults with Turner Syndrome into the adult care setting.
<u>Recommended Approach for Planning for Pediatric Practices</u>	This tool provides pediatric practices with a guide for how to begin the transition process for patients Turner Syndrome.	The <u>recommended approach</u> is to be used by pediatric practices as they plan for transitioning patients into adult care.

<p><u>Adult Care Recommendations for Screening and Assessment</u></p>	<p>This form serves as a resource to inform the patient about screening recommendations and other assessments needed in adulthood and which clinician is responsible for conducting it.</p>	<p>The <u>chart</u> should be used to inform the patient about which clinician should be responsible for conducting various screenings and other assessments.</p>
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