

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> |
|---|---|---|