HEALTH CARE TRANSITION FOR PATIENTS WITH TURNER SYNDROME: RECOMMENDED APPROACH TO PLANNING FOR PEDIATRIC PRACTICES
TURNER SYNDROME
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ADAPTED FROM “GOT TRANSITION” — SIX CORE ELEMENTS OF HEALTH CARE TRANSITION:

1) Have a consistent, practice-wide policy or a planned approach for transitioning patients.
   • Develop a written plan or approach to health care transition. Some examples of transition policies can be found on the “Got Transition” website.
   • Share the transition policy with patients and families (“health care transition is a positive part of preparation for a successful and healthy adult life;” “we care about you and want to be sure you are prepared as you mature and go into your adult life”).

2) Have a youth registry to identify who is ready to start the transition process as well as to track progress and outcomes.

3) Transition Preparation/Readiness Assessment
   • Identify a skill set for independent self-care (suggested language for patients: “we want to be sure you are prepared to transition/we want to help prepare you for transition”).

4) Transition Planning
   • Introduce health care transition planning for girls with Turner syndrome — including planning both for increasing self-management and for ultimate transfer to adult care. This should be initiated at or around age 12 years, or when puberty/puberty induction begins. Patients and families should participate in ongoing self-management education throughout the teenage years.
   • Individualize transition skills education according to the needs of the patient. A skill set for young women with Turner syndrome can be found here.
   • Develop a clear transition action plan with shared goals.
   • Help parents with transition roles and assignments within the action plan.
   • Work with the patient to develop and review portable medical summary and emergency care plan.

5) Transition and Transfer of Care
   • Plan for the transfer to adult care, according to the practice policy. Ultimately, the transition process culminates in the transfer from a pediatric health care model to an adult health care model.
   • Work with the patient and family to clearly identify appropriate adult providers.
   • Exchange information with receiving adult care providers.
   • Send transition package of necessary medical records.

6) Transition Completion
   • Continue to provide medical advice and support to the young adult patient until the transition is complete.
   • Put measures in place in the pediatric practice to “close the loop” and ensure that the transitioning patient is established in adult care.