



## TALKING TO YOUR CARE TEAM

Taking over responsibility for personal medical care can be an overwhelming process for individuals. Early planning and preparation can reduce the stress during the time of moving towards self-sufficiency.

### **These steps can ensure a smooth transition:**

**Have Doctors Directly Address the Individual, Not Their Parents or Caregivers.** If the individual with MPS or ML prefers to have someone else present, ground rules for the conversation should be set early and maintained. When going alone, preparation and organization can reduce stress and intimidation during the visit. While it may seem like parents and caregivers are experts, they started with very little information and learned along the way!

**Always Bring Health Records.** With rare disease, it is important to provide as much information as possible to healthcare providers. The files can be stored in binders or on a flash drive for easier transport and copies can be made at the office. This will save time and keep everyone informed. This benefits everyone involved.

**Take Notes.** Listening to a doctor speak can sometimes be confusing and hard to follow. It is important to record (either through a recording device or writing notes) the pertinent information provided for later review. The healthcare professional should also be available to provide their notes for review as well. If they offer MyChart or another electronic portal to record information, request access.

**Ask Questions!** Healthcare professionals are there to help and provide answers. Before the appointment prepare a list of questions to give to them, or read them aloud. If questions arise after the appointment, follow up with the doctor, and don't be embarrassed!