

When pediatric endocrinology patients “graduate” to an adult practice, they should be prepared to assume their adult healthcare responsibilities. A patient’s transition from pediatric to adult endocrinology care is a long-term process, rather than a one-time event, and the Transition Toolkit provides an organized approach to this process.

The Transition Toolkit is intended to be used by pediatric endocrinology healthcare providers and their patients throughout the adolescent years. The Transition Checklist and Timeline and Personal Health Diary help educate patients, their families, and pediatric healthcare providers about the evolving impact of chronic conditions throughout adolescence, and they encourage patients to practice independent health management behaviors. In addition, the Transition Passports that are completed prior to the patient’s last pediatric visit facilitate the transfer of health information to the adult care provider and provide recommendations for future screening and follow-up.

This starter kit contains the following Transition Toolkit materials:

- Transition Toolkit File Folder
- Transition Checklist and Timeline
- Personal Health Diary
- Patient Binder
- Transition Passport
- Turner Syndrome Passport
- Childhood Cancer Survivor With Endocrine Late Effects Passport
- Complex Pituitary/Other Endocrine Disorders Passport
- Certificate of Graduation

The following pages contain instructions for using these materials. An order form can be found on the last page of this overview.

Acknowledgements

The Transition Toolkit was developed under the leadership of:

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Transition Toolkit File Folder

Where should this be kept?

An office filing cabinet

How is this used?

This folder can be used to save hard copies of the Transition Checklist and Timeline, Personal Health Diary, Transition Passports, and Certificate of Graduation in your files.

It is a good idea to keep at least 1 copy of the Transition Toolkit materials on file at all times. Even if you have only 1 copy left, you can photocopy it for patients as needed.

In addition, you can save copies of the order form (found on the last page of this overview) in the folder for future use.

Transition Checklist and Timeline

Where should this be kept?

The patient's chart

How is this used?

The Transition Checklist and Timeline is a checklist of patient counseling activities for you to initiate at:

- Early-stage transition – grades 5 to 7 (ages 10 to 12 years)
- Mid-stage transition – grades 8 to 10 (ages 13 to 15 years)
- Late-stage transition – grades 10 to 12 (ages 16 to 19 years)

The counseling activities are organized according to the following categories:

- Knowledge/self-advocacy
- Independent healthcare behaviors
- Bone health
- Lifestyle issues
- Psychosocial wellbeing
- Sexual health
- Educational and vocational planning
- Implementing the transition to adult care

As you complete each counseling activity, check the box labeled “yes” and write the date in the space below. If a particular activity is inappropriate or not applicable to your patient, check the box labeled “N/A” and use the space below to provide a brief explanation (eg, “patient is not yet mature enough,” “not possible due to patient’s cognitive deficits”).

Tips for using the Transition Checklist and Timeline

The following tips may be helpful as you use the Transition Checklist and Timeline:

- Keep in mind that the counseling activities for each stage of transition can be spread among multiple office visits. For example, you can choose to focus on the “Knowledge/self-advocacy” and “Independent healthcare behaviors” categories at one visit, and counsel the patient on other categories at the next office visit.
- Do prioritize the counseling activities as needed. For example, if bone health is a particular concern for a patient, you may choose to focus on this category first or even at every single office visit.
- The grade and age limits for each stage of transition are intended only as a guide. Each person matures at a different rate, and certain patients may reach early-, mid-, and late-stage transition earlier or later than other patients. Feel free to tailor the timeline to individual patients as needed.
- Note that some of the counseling activities will never be appropriate for patients with severe cognitive deficits or developmental delays. In these cases, check the box labeled “N/A” and provide a brief explanation in the space below.

Personal Health Diary

Who keeps this?

The patient

How is this used?

The Personal Health Diary is placed in the Patient Binder (see next page) and presented to patients during mid-stage transition.

When you give this to your patient, you can explain, “I think you’re mature enough to start keeping track of your own medical appointments and health records. The Personal Health Diary will help you do this. I’d like you to update it regularly and bring it to all of your medical appointments. It’s very important for you to bring it to your appointments—not only because we can help you update it, but also because it’s a good way to share information with us.”

Be sure to explain each section and/or help your patient complete the first few entries of each section as an example. The Personal Health Diary contains the following sections:

- Contact information. This section includes fields for patients to list personal contact information and contact details for their insurance provider, physicians, and pharmacy. The “Other” field can be used to list other healthcare providers or relevant medical advocacy groups.
- Healthcare appointments. Patients can use this section to track upcoming healthcare appointments and list questions to ask at each visit. Examples of “outcomes, action items, and next steps” that can be listed in this field include “Schedule follow-up appointment in 3 months,” “Fill new prescriptions,” and “Missed this appointment—reschedule ASAP.”
- Medicines, devices, and other therapies. This section contains fields to list the names of medications or other therapies, their indications, dosages (as applicable), and start and end dates.
- X-rays/procedures/surgeries/special lab testing. Patients can use this section to record their test or procedure results.
- Personal health measurements. Some patients may need to measure their height, weight, blood pressure, or other health parameters on a regular basis. This section of the Personal Health Diary includes fields for them to record their results.
- Insurance and reimbursement correspondence. Patients can use this section to track their insurance and reimbursement correspondence and list the next steps or outcomes.
- Calendars. Patients can refer to these yearly calendars when scheduling new appointments or tracing the chronology of symptoms or treatments.

Tips for encouraging patients to use the Personal Health Diary

Adherence is always an issue when asking patients to adopt new behaviors. The following tips may help encourage your patients to use the Personal Health Diary consistently:

- Reinforce the importance of the Personal Health Diary by asking about it at each visit. If you neglect to ask about it, your patients may assume it is not important.
- Be sure to ask your patients if they have any questions about how to use the Personal Health Diary. If they do not understand how to use it, they will not use it.
- Remember to praise your patients for being responsible and mature enough to maintain their Personal Health Diary!

Patient Binder

Who keeps this?

The patient

How is this used?

The Patient Binder holds the Personal Health Diary, and its binder rings allow for easy addition and removal of diary pages. In addition, it serves as a central repository for health information: laboratory reports, patient handouts, and the completed Transition Passports (see next page) can be 3-hole punched for the binder rings, while prescriptions and brochures can be placed in the binder's inside pockets. The foldover flap protects the privacy of patient health information by holding the binder closed when needed and preventing materials from falling out.

The Patient Binder is available in 5 different colors, and patients can choose the color they prefer.

Transition Passport

Where should it be kept?

The original copy should be given to the patient at the last pediatric visit, and a copy should be placed in the patient's chart or health record.

How is it used?

The Transition Passport marks your patient's passage to adult care and facilitates the transfer of health information to the adult care provider. Several sections (such as clinical diagnoses and the targeted risk assessment) can be completed once the patient reaches late-stage transition; all other sections (such as recent laboratory test results) should be completed just prior to your patient's last pediatric visit.

Be sure to select the appropriate Transition Passport for your patient:

- Turner Syndrome Passport. This passport for girls with Turner syndrome includes sections on clinical diagnoses and treatments, recent laboratory test results, and a targeted risk assessment.
- Childhood Cancer Survivor With Endocrine Late Effects Passport. This passport contains fields for the patient's cancer history, endocrine/metabolic and non-endocrine late effects, and current treatments. In addition, there are sections for recent laboratory test results and a targeted risk assessment.
- Complex Pituitary/Other Endocrine Disorders Passport. This passport can be used for all other endocrine patients. There are fields for the patient's medical history, clinical diagnoses, treatments, and potential endocrine/metabolic abnormalities that require surveillance. As with the other 2 passports, there is laboratory test results section and a targeted risk assessment.

The back cover of all 3 Transition Passports contains lists of recommendations for adult care providers. Edits, deletions, and additions can be made to these lists as needed.

Before sharing the completed Transition Passport with your patients, be sure to make a copy for their chart. Advise your patients to keep the original in their Patient Binder and bring it to their adult care visits—that way, even if their chart is misdirected, they will still have a copy to share with their new physicians.

When you share the Transition Passport with your patients at their last pediatric visit, you can use it to counsel them on their current health status, describe future health risks, and explain what they can expect at their adult care visits.

Tips for completing the Transition Passports

The following tips may be helpful as you complete the Transition Passports:

- Once your patient reaches late-stage transition, the Transition Passport should be considered a work-in-progress. Certain sections, including the clinical diagnoses, treatments, and targeted risk assessment, can be completed in an ongoing basis. All other sections should be completed just prior to the patient's last pediatric visit.
- To save time, you can ask your patient to complete the "General" section of the Transition Passport. This section includes fields for the patient's contact, insurance, and demographic information.
- If your patient's life goals are limited by developmental delays or cognitive deficits, you may wish to indicate this in the respective section.

- To help the adult care provider identify abnormal test results, you may wish to place an asterisk next to them.
- At times, you may wish to provide additional information (such as lists of medications used in the past) to the adult care provider. To save time, photocopy this information from the patient's Personal Health Diary whenever possible.
- Electronic health records (EHR) can help you update patient forms and charts more efficiently. If your practice is planning to establish an EHR system, consider incorporating the Transition Passports into the system. It may be possible to pre-populate sections of the Transition Passports with existing data from the patient's chart.

Certificate of Graduation

Who keeps this?

The patient

How is this used?

The Certificate of Graduation is presented to your patients at the end of their last pediatric visit to provide closure to their pediatric phase of care. Use of the Certificate is optional—if you feel that it is inappropriate due to your patient's age, level of maturity, or personality, you do not need to use it.

Transition Toolkit Order Form

Please provide your contact information in the spaces below:

| | |
|-------------|--|
| Name | |
| Affiliation | |
| Address | |
| Phone | |
| Fax | |
| E-mail | |

Each Transition Toolkit item is packaged in units of 5. Please indicate the number of units you would like to order. A maximum of 10 units of each item can be ordered per month. All orders are free of charge.

| Item | Number of units |
|--|-----------------|
| Transition Checklist and Timeline | |
| Personal Health Diary | |
| Patient Binder | |
| Turner Syndrome Passport | |
| Childhood Cancer Survivor With Endocrine Late Effects Passport | |
| Complex Pituitary/Other Endocrine Disorders Passport | |
| Certificate of Graduation | |

Please give this completed form to your local Genentech sales representative.