

Personalized Checklist for Alison's Caregiver

Thank you very much for taking the time to complete the Down Syndrome Clinic to You (DSC2U) intake form. **We used your responses to create this personalized checklist of information, resources, and recommendations for Alison.** The "Why" after each recommendation will explain why each suggestion was made for Alison.

We know Alison's health and wellness are very important to you, and we hope these resources will be helpful as you oversee her care. At the same time, a long list can sometimes feel a bit overwhelming. We encourage you to talk through the contents of this checklist with Alison's primary care provider and other trusted caregivers or family members who may help you with Alison's care.

The suggestions in this checklist were generated by a computer, based on your answers to the DSC2U intake form. The checklist was not prepared or reviewed by a clinician specifically for Alison but was assembled from information that was carefully chosen by a team of medical experts. Whenever possible, the information in this document was drawn from national healthcare guidelines for people with Down syndrome. The information has been reviewed to make sure it is consistent with current best practices.

As a reminder, this checklist does not establish a health care provider-patient relationship. It is not an attempt to practice medicine or provide specific clinical advice. It is intended to provide useful information to you and Alison's primary care provider for reference and educational purposes only. The content of this checklist is not meant to be complete or absolute or to be a substitute for professional medical advice, diagnosis, or treatment. It should not be used to make a diagnosis or to replace or overrule a qualified health care provider's judgment.

While you and your primary care provider will not have the opportunity to discuss clinical or personal information about Alison with physicians at Massachusetts General Hospital, we would be happy to answer any technical questions about DSC2U at dsc2u@mgh.harvard.edu.

We have done our best to identify the best information and resources currently available for people with Down syndrome and to try to select it in a way that could be helpful for you and your loved one. We very much hope that you find this information empowering so that Alison can continue to have a healthy, meaningful, and satisfying life.

With all good wishes,

The DSC2U team
08/04/2020

You might choose to check each item when completed for Alison.

Labs, Tests, and Procedures for Alison

It is recommended that you ask Alison's doctor to consider ordering the following during the upcoming routine physical exam:

- Audiogram/hearing test.** Alison is due for a hearing test. [More information on hearing loss and Down syndrome.](#) [Evaluation and treatment options \[video\].](#) [↗](#)

Why? "Up to 75 of every 100 Individuals with Down syndrome have hearing loss; the American Academy of Pediatrics recommends all individuals between the ages of 1 and 21 have an annual audiogram. You indicated that Alison did not have an audiogram within the past year.

- Eye exam.** Alison is due for a vision test by an eye doctor specialist. [More information on vision changes and Down syndrome.](#) [Evaluation and treatment options \[video\].](#) [↗](#)

Why? Up to 80 of every 100 children with Down syndrome have eye problems; the American Academy of Pediatrics recommends all individuals between the ages of 13 and 21 to have an eye exam every three years or more frequently, if needed. You indicated that Alison did not have an eye exam within the past three years.

- Sleep study.** Alison has never had a sleep study. The American Academy of Pediatrics recommends that all children with Down syndrome have a sleep study. [Testing for sleep apnea is important with many medical consequences if apnea is present and untreated \[video\].](#) [↗](#) [Here is how caregivers can prepare for sleep studies.](#) [↗](#) [Here is a social story that Alison can use prepare for the sleep study.](#) [↗](#)

Why? Of every 100 people with Down syndrome, up to 75 are expected to have obstructive sleep apnea, while 25 do not. Research has also shown that patients with Down syndrome may lose up to 9 IQ points within a year when their apnea is untreated. Since Alison hasn't had a sleep study yet, you should discuss this with Alison's doctor.

- Thyroid function tests (blood work).** Alison may be due for her thyroid check. Further testing is needed. [Treatment options are available for those with a confirmed diagnosis \[video\].](#) [↗](#) [More information on thyroid conditions in Down syndrome.](#) [↗](#)

Why? You indicated that within the past 12 months, you are not sure whether or not Alison has had her thyroid levels drawn. The American Academy of Pediatrics recommends that everyone with Down syndrome have their thyroid levels checked once annually. Please discuss this with Alison's provider.

- Hemoglobin level (blood work).** You indicated that you are not sure whether Alison has had a hemoglobin tested in the past 12 months. [Further testing is needed.](#) [↗](#) If Alison is found to have anemia, [treatment options may include increasing iron in the diet](#) [↗](#) or starting an iron supplement. Your provider might order a complete blood count (rather than just a hemoglobin level). [If so, don't be alarmed if some of the values are slightly abnormal.](#) [↗](#)

Why? Children with Down syndrome are at risk of developing iron-deficiency anemia, which means that their hemoglobin, which is how oxygen is transported in our bodies, is low because the body isn't receiving enough iron to make the hemoglobin. Anemia can also affect cognitive function. The American Academy of Pediatrics recommends testing the hemoglobin level every year, which will tell us whether or not anemia is present. If this is the case, your provider may consider adding iron to your diet, through diet or supplements, which helps resolve the anemia.

- Dental visit.** Alison might be due for a dental visit. [Regular dental care is important for all people with Down syndrome.](#) [↗](#) [Here is a Webinar \[video\]](#) [↗](#) [on common dental issues for people with Down syndrome.](#) [Please see this handout for how to prepare for](#)

a dental visit. [↗](#) And, a book for Alison to read as she prepares for her visit. [↗](#) And, here is a [Webinar \[video\]](#) [↗](#) in case orthodontic care is needed.

Why? You indicated on the intake that you are unsure if Alison has seen a dentist in the past 6 months.

- Flu shot.** [More information on vaccines and Down syndrome.](#) [↗](#)

Why? The same precautions and contraindications for the general population apply to people with Down syndrome. Alison's caregiver indicated that Alison gets a flu shot "some years."

- HPV vaccine.** [More information on vaccines and Down syndrome.](#) [↗](#)

Why? Experts specializing in Down syndrome recommend that boys and girls between the ages of 9 and 26 receive the standard three doses of the human-papilloma virus (HPV) vaccine, to protect against HPV infection, regardless of sexual activity. You indicated that Alison has not had an HPV vaccine in the past.

New or Known Conditions/Diagnoses to be Considered for Alison

There are many medical, behavioral, and mental health conditions that can co-occur with Down syndrome. Sometimes, it is not just Down syndrome! Proper evaluation and treatment of co-occurring conditions can result in healthier and happier lives. It is recommended that you discuss these potential conditions with Alison's doctor during the upcoming routine physical exam:

- Obsessive-Compulsive Disorder (OCD).** Check out [chapter 16 of this book](#) [↗](#) to see if it fits with Alison's behaviors.

Why? People with Down syndrome may sometimes experience obsessive-compulsive disorder, which is a common mental health condition characterized by repetitive, uncontrollable, and distressing thoughts or behaviors. You indicated that within the past 6 months, Alison has experienced ritualistic compulsive behaviors and that Alison finds these distressing, or they disrupt her daily routine. We recommend exploring this further with Alison's provider. Treatment is available for those with a diagnosis of obsessive-compulsive disorder.

- Dry skin (xerosis).** [More information and treatment options](#) [↗](#) for dry skin in people with Down syndrome.

Why? You indicated that within the past month, Alison has experienced dry skin. This may be suggestive of dry skin (xerosis), among other things. Dry skin is very common in people with Down syndrome. Consider talking to Alison's provider about different treatments (such as over-the-counter moisturizers).

- Acne.** Here is [a handout](#) [↗](#), and [another one](#) [↗](#).

Why? You indicated that one of your current medical concerns for Alison is acne. Acne can certainly cause a lot of stress and self-consciousness. Consider discussing this with Alison's provider and talking about whether or not a dermatology referral would be helpful.

- Seasonal allergies.** Read [pages 83-85 in this book](#) [↗](#) for information and treatment options on seasonal allergies in people with Down syndrome.

Why? You indicated that seasonal allergies is one of your current medical concerns for Alison. These allergies can be common in people with Down syndrome. A range of over-the-counter medications may help lessen some of these symptoms. Talk to Alison's provider about your options.

- Menstrual (period) complaints.** Read [chapter 5, pages 96-102 in this book](#) to learn more about some treatment options for menstrual complaints in women with Down syndrome.

Why? You indicated that within the past month Alison has experienced irregular periods. Treatments are available for menstrual complaints; talk to Alison's provider about these issues and the different treatment options that may be available.

Health and Wellness Resources for Alison

Here are some specific resources based on your requests.

- Puberty and Sexual Development.** [This book](#) is great for you, the caregiver, especially chapter 5. Consider [this book](#) for Alison.

Why? You indicated that Alison had concerns about body development (puberty).

- Food assistance.** [Here is a resource](#) and [another one](#) to help assess Alison's eligibility for food assistance. [Here is a handout](#) that may offer tips on how to eat healthy on a budget.

Why? You indicated that within the past year you are not sure if you have had enough money to purchase food for Alison, or that food would run out before more was purchased.

Nutrition Recommendations for Alison

People with Down syndrome, in general, have slower metabolism. Focusing on healthy eating, at all ages, is important. Sometimes, making just a few tweaks in one's diet can go a long way. Based on your responses, here are some suggestions:

- Ask Alison's doctor if she should have **more calcium in the diet.** [This handout](#) details daily calcium needs based on age, and foods you can offer to ensure that Alison is meeting her needs. Also, individuals should take between 400 - 1000 international units of Vitamin D a day based on their age, which can be consumed through food, pill, or supplement.

Why? You indicated that Alison does not meet her daily calcium needs.

- Ask Alison's doctor about **increasing fruit and vegetables in Alison's diet.** [Here are 20 ways to help encourage fruit and vegetable intake.](#) [Here is a handout with some tips](#) to increase fiber in her diet.

Why? You indicated that Alison is not meeting her daily fruit and vegetable goal. It is also possible that she is also not meeting her fiber needs as a result.

- This handout has [tips for healthy eating](#). Also consider reading [this book](#) for a detailed overview on healthy nutrition for people with Down syndrome.

Why? Healthy eating is important for children with Down syndrome.

Life Skills Suggestions for Alison

One step at a time, Alison can become increasingly more independent. Based on your responses, here are some specific resources to help achieve those life skills that you wanted Alison to work on next.

For more information on transitions related topics, please visit this excellent "got transitions" website , or this resource specific website, or this book.

Goals for Alison to work on now:

- To learn **where to find her doctor's phone number**. [Here is a resource to help.](#) ↗
- To learn **how to ask questions of her doctor**. [Here is a resource to help.](#) ↗
- To learn **how to describe how she is feeling to her doctor**. [Here is a resource to help.](#) ↗
- To learn **how to find her medications**. [Here is a resource to help.](#) ↗
- To learn **what each of her medications is for**. Your doctor can help educate you about your medications. [Here is a video to help.](#) ↗
- To learn **how to take her medications every day on her own**. [Here is a resource that can help you remember.](#) ↗
- To learn **how to refill her prescriptions on her own**. [Here is a resource for practice.](#) ↗
- To learn **how to swallow whole pills**. [Here is a resource to help.](#) ↗
- To learn about **the differences between healthy and unhealthy foods**. [Here is a resource to help.](#) ↗
- To learn **how to call 911 if there is an emergency**. [Here is a resource to help.](#) ↗
- To **exercise regularly**. [Here is a resource to help](#) ↗ and a video to watch ↗.
- To learn **how to provide her personal information when needed**. [Here is a resource to help.](#) ↗
- To learn **how to tell the difference between a stranger and a friend**. [Here is a resource to help.](#) ↗
- To learn **how to use public transportation on her own**. [Here is a resource to help.](#) ↗ We'd also recommend that you read [pages 231-234 of this book](#) ↗.
- To learn **how to do household chores**. [Here is a resource to help.](#) ↗
- To learn **how to manage her period**. [Here is a resource to help.](#) ↗
- To **understand sexual boundaries and privacy**. [Here is a great book for caregivers.](#) ↗ [Here is a guide to dating for people with Down syndrome.](#) ↗ Also, consider the [Circles® curriculum](#) ↗, also available as the [Circles App™](#) ↗.
- To learn **how to brush her teeth on her own**. [Here is a resource to help.](#) ↗
- To be able to **use a public restroom on her own**. [Here is a resource to help.](#) ↗
- To **find her insurance card**. [Here is a resource to help.](#) ↗

- To **have a plan for what she will do after finishing high school**. Consider reading [pages 53-73 of this book](#). Here is [additional information on life after high school](#), and some [college options](#).

Goals for Alison to work on later:

- To be able to **prepare her own meals**. [Here is a cookbook designed specifically for people with Down syndrome](#).
- To be able to **do her own laundry**. [Here is a resource to help](#).

Education/Therapy Resources for Alison

Each year, researchers are better understanding how people with Down syndrome learn. Based on your requests, here are some resources for you to consider for Alison.

- Math skills**. Check out [this book](#). And, here's [a book](#) on the latest research on how children and adolescents learn.

Information and Resources for Alison's Caregiver

Here are some specific resources based on your requests.

- Best Buddies**. [More information on their webpage](#). [Find programs in your state](#).

Why? You requested more information on Best Buddies.

- GiGi's Playhouse**. [More information on their webpage](#). [Find locations near you](#).

Why? You requested more information on GiGi's Playhouse.

- LuMind Research Down Syndrome Foundation**. [More information on their webpage](#). [Join their mailing list](#).

Why? You requested more information on LuMind Research Down Syndrome Foundation.

- Local Down syndrome organization**. You can access [this link](#) to find a list of all the Down syndrome organizations in the U.S. Check to see if there might be one near you!

Why? You indicated that you are not yet connected to a local Down syndrome organization.

- Genetic Diagnosis**. You indicated that Alison has trisomy 21, but you would like more information about the genetics. [Here is a resource for more information](#).

Why? You indicated that you would like more information on the genetic diagnosis that has resulted in Alison having Down syndrome.