

Appendix B. Caregiver Checklist



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 Allison.** The "Why" after each recommendation will explain why each suggestion was made for Allison.

We know Allison'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 Allison's primary care provider and other trusted caregivers or family members who may help you with Allison'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 Allison 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 Allison'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 Allison with physicians at Massachusetts General Hospital, we would be happy to answer any technical questions about DSC2U at [dsc2u@mgh.harvard.edu](mailto: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 Allison can continue to have a healthy, meaningful, and satisfying life.

With all good wishes,

The DSC2U team

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

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## Labs, Tests, and Procedures for Allison

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

**Dental visit.** Allison is 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 Allison 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 Allison has not seen a dentist in the past 6 months.*

**Flu shot.**

*Why? You indicated that Allison gets her flu vaccine “most years.” Experts recommend that people with Down syndrome get their flu shots every year, the same as everyone else in the general population. If this has not been done this year, we recommend discussing this with Allison’s provider.*

**Pneumonia vaccine.**

*Why? Experts specializing in Down syndrome recommend that adults with Down syndrome receive pneumonia vaccines at an earlier age. Individuals with Down syndrome are at an increased risk of developing pneumonia due to a slightly weaker immune system. You indicated that Allison has not had a pneumonia vaccine in the past. We recommend discussing this with Allison’s provider.*

**SLP and Neuropsych referral.** Talk to Allison’s provider about having Allison referred to a Speech and Language Pathologist and a neuropsychologist to assess Allison’s speaking abilities.

*Why? You indicated that Allison has experienced a change in her ability to speak, and you also indicated that there has been a decrease in Allison’s speaking clarity or fluency and Allison is speaking less now. Seeing a speech and language pathologist/therapist and a neuropsychologist may help figure out why these changes have happened and what therapies may help Allison.*

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## New or Known Conditions/Diagnoses to be considered for Allison

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 Allison’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 Allison’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, Allison has experienced ritualistic compulsive behaviors and that Allison finds these distressing, or they disrupt her daily routine. We recommend exploring this further with Allison’s provider. Treatment is available for those with a diagnosis of obsessive-compulsive disorder.*

**Bone and joint conditions.** Check out [page 181-185 of this book](#). Also, [this handout on gout](#) might be relevant.

*Why? You indicated that within the past month, Allison has experienced joint stiffness, joint swelling, joint pain. These symptoms may be caused by several different conditions that cause joint problems, including gout, osteoarthritis, or another condition causing inflammation. Allison may require some blood work and some X-RAYS to come to a diagnosis. Consider discussing this with Allison’s provider.*

- Eczema (atopic dermatitis).** [More information on eczema and its treatment.](#) [↗](#)

*Why? You indicated that within the past month, Allison has experienced eczema. This may be suggestive of eczema, among other things. Consider talking to Allison's provider about different treatments (such as over-the-counter moisturizers) to help soften some of the symptoms of eczema.*

- Skin boils (Hidradenitis suppurativa).** Here is [a handout](#) [↗](#). Also, read [pages 71-73 of this book](#) [↗](#).

*Why? You indicated that within the past month, Allison has experienced skin boils under armpits and groins. This is a common, but treatable, skin condition in people with Down syndrome. Skin boils that cause scarring are called hidradenitis suppurativa. Check out the resources above for more information. Talk to Allison's provider about this. Allison may also need to see a dermatologist for more advanced treatment, if necessary.*

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

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

- 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 Allison has experienced irregular periods and severe cramps. Treatments are available for menstrual complaints; talk to Allison's provider about these issues and the different treatment options that may be available.*

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## Health and Wellness Resources for Allison

Here are some specific resources based on your requests.

- Challenging behaviors.** Consider reading [chapter 19 of this book](#) [↗](#) or watching this [webinar \[video\]](#) [↗](#) for behavioral tips and advice.

*Why? You indicated that within the past six months, Allison has experienced temper tantrums, outbursts, or meltdowns. Teens and adults with Down syndrome may sometimes experience disruptive or dysregulated behavior. Positive reinforcement, encouragement and structure may help support more positive behavior in people with Down syndrome. Several techniques and tips for doing this are conveyed in the book linked above.*

- Dating and Social Boundaries.** [This book](#) [↗](#) and [this book](#) [↗](#) are great for you, the caregiver. Consider [this book](#) [↗](#) for Allison. [This mobile app](#) [↗](#) is also a great learning tool to complement [this sexual education curriculum](#) [↗](#) for persons with intellectual disabilities.

*Why? You indicated that Allison had questions about dating or social boundaries.*


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

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



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## Nutrition Recommendations for Allison


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 Allison'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 Allison 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 Allison does not meet her daily calcium needs.*

- Healthier snacking**. [This handout](#)  is a great visual guide to encourage healthy snack choices. [Here are some options for healthy, low-calorie snacks](#). 

*Why? You indicated that Allison likes sweets or crunchy foods for snacks.*

- Consider reading [this book](#)  for a detailed overview on **healthy nutrition for people with Down syndrome**.

*Why? Healthy eating is important for people with Down syndrome.*







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## Life Skills Suggestions for Allison

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

- 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 take her medications every day on her own**. [Here is a resource that can help you remember](#). 
- To learn **how to call 911 if there is an emergency**. [Here is a resource to help](#). 
- To learn **how to provide her personal information when needed**. [Here is a resource to help](#). 
- To learn **tell the difference between a stranger and a friend**. [Here is a resource to help](#). 

- To learn **how to do household chores**. [Here is a resource to help.](#) ↗
- To be able to **bathe/shower herself**. [Here is a resource to help.](#) ↗

#### Goals for Allison to work on later:

- 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 refill her prescriptions on her own**. [Here is a resource for practice.](#) ↗
- To learn about **the differences between healthy and unhealthy foods**. [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 be able to **prepare her own meals**. [Here is a cookbook designed specifically for people with Down syndrome.](#) ↗
- 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](#) ↗.

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## Education/Therapy Resources for Allison

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 Allison.

- Adaptive living skills**. Check out [chapter 9 in this book](#) ↗.
- Vocational skill/employment opportunities**. Click here for an overview of [employment options](#) ↗. Also, check out the resources of the [Your Next Star campaign](#) ↗, including [resources for applicants](#) ↗ and [employers](#) ↗. Here are more resources and success stories from [#DSWORKS®](#) ↗. For more information on employment, check out [this website](#) ↗ and [this handout](#) ↗.

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## Information and Resources for Allison's Caregiver

Here are some specific resources based on your requests.

- The Arc**. [More information on their webpage.](#) ↗ [Find your local Arc chapter.](#) ↗

*Why? You requested more information on the Arc.*

- DS-Connect®**. [Consider registering Allison at DS-Connect](#) ↗ to connect with researchers and healthcare providers.

*Why? You requested more information on DS-Connect®.*

- 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.*

- Special Needs Trust/ABLE Accounts.** Check out [this website](#) or [this book](#) for more information on setting up a special needs financial planning. Some states enable parents and caregivers to set up an ABLE account. Learn more about ABLE accounts [here](#) and check out [this website](#) for a comparison of state ABLE accounts. Also, [here](#) you can see a chart comparing ABLE accounts and third-party special needs trusts and also read up on some pros and cons of ABLE accounts.

*Why? You indicated that you would like more information on setting up a special needs trust or an ABLE account for Allison.*

- Supports for brothers and sisters.** Check out this [book](#), [webinar](#), and [YouTube channel](#). Adult-aged siblings might find the [Sibling Leadership Network](#) to be helpful, in addition to this [toolkit](#).

*Why? You indicated that you would like more information on supports for brothers and sisters.*

- Moving out/residential options.** Check out [this book](#) about different residential options available for adults with Down syndrome.

*Why? You indicated that you would like more information on moving out and residential options.*