



What are her current health conditions?

Does he take any medications?

Where does he get his prescriptions filled?

How often does she need to go to the doctor?

What specialists does she see?

Completing the Health Section

Because the healthcare needs of older individuals with Down syndrome can be complex and sometimes misdiagnosed, it is important to understand the impact mental health and well-being has on physical health. Many families do not have access to physicians with a comprehensive understanding of the healthcare needs for adults with Down syndrome. In the 'Resources & More' section of this toolkit, you will find two documents describing common health conditions for older adults with Down syndrome. These are appropriate to copy and share with your sibling's healthcare provider:

- 1) "*Health Issues for Adults with Down Syndrome*", from the Adult Down Syndrome Center which provides critical information in understanding mental and physical health in adults with Down syndrome and,
- 2) "*Health Conditions associated with aging and end of life of adults with Down Syndrome*" from the NIH, which is a more clinical guide of the changes adults with Down syndrome experience as they age.

The pocket folder provides a place to keep the most recent records of doctor visits, lab and test results, copies of insurance cards, etc. The worksheets provide a place to record your sibling's medical history; the names of doctors and specialists your sibling sees; a place to list medications he/she is taking and which condition the medication is treating; and information about self-talk, routines and "grooves" along with an hourly log. Completing these pages with your parents, giving as much detail as possible, is going to make any transition of primary care much easier. Please go to our website to download additional forms if necessary.

Keeping the information in one binder and taking it to every health care appointment will give the provider an important overview of your sibling's health. It can also help the physician make a more accurate diagnosis.

Dr. Brian Chicoine and Dr. Dennis McGuire, who founded the Adult Down Syndrome Center in Chicago, IL, have said it best, "Health is defined as being more than the absence of disease; it involves physical, mental, and spiritual well-being. Developing an understanding of how physical health problems contribute to mental health issues and evaluating patients for these connections are essential to providing quality health care." Their books, *Mental Wellness in Adults with Down Syndrome* and *The Guide to Good Health for Teens & Adults with Down Syndrome* should be mandatory reading for everyone who loves someone with Down syndrome.

Medical History

Does your sibling have any allergies to medications?
(If yes, list here) YES NO

Does your sibling have any food allergies?
(If yes, list here) YES NO

Does your sibling have any chronic health conditions? YES NO

(Please Circle All that Apply & Enter Treating Physician on Medical Professionals Page)

Diabetes	Celiac Disease
Asthma	Sleep Apnea
Seizures	Depression
Heart Condition	Thyroid Disease
G I Issues	Hearing Impairment
Vision Impairment	Skin Conditions
Joint Problems	Atlanto-axial instability

Any other Conditions? (Enter Treating Physician on Medical Professionals Page)

Diet & Exercise

Does your sibling struggle with being overweight? YES NO

Follows specific food guidelines? YES NO

Have a regular exercise program? YES NO

Medical History

Has your sibling had surgery or been hospitalized in the past ten years?

List the year & the cause

Does your sibling have any psychological/emotional difficulties? (Please Circle All that Apply & Enter Treating Physician on Medical Professionals Page)

Depression

Anxiety

Self-Talk

OCD

Behavioral Issues

PTSD

Agitation

Physical Aggression

Memory loss

Loss of skills

Medication Information

Medication name:

Medication purpose:

Dosage:

Prescribing doctor:

Comments:

Medication Schedule

	Medication name	Dosage	Condition for	Prescribed by	Special Instructions	Possible Side Effects
Early AM						
Mid-morning						
Lunch						
Mid-afternoon						
Evening						

Your sibling may exhibit odd or repetitious behaviors that others find disturbing. These are referred to as “grooves” or “stereotypic behaviors”. Grooves can be a strength, allowing people to organize their rooms and personal items, and present themselves to the world in a neat and dignified fashion. Grooves may also increase independence at home or work by following through reliably with self-care or workplace tasks, once these activities are part of a daily routine. However, a groove can also be a safety valve allowing people to have some outlet when they are under stress. In these instances people can get stuck in certain set patterns of behavior that may be unproductive. These become more problematic when the grooves interfere with essential life activities or unforeseen schedule changes (i.e. Friday night is pizza night *no matter what*). Often these behaviors increase when your sibling is stressed or very tired. Related to this are stereotypic behaviors, which may not appear to be under conscious control. This could include repetitious body movements: hand-flapping, rocking, rubbing, or unusual noises.

Does your sibling have any grooves or stereotypic behaviors?

What behaviors occur if the routine is changed?

Does your parent have any strategies to redirect these if inappropriate in a certain situation?

Suggestions for reducing behaviors that are worrisome:

- Establish a secret gesture with your sibling that reminds her in a positive fashion, such as finger to the lips for “quiet mouth” if noises are an issue.
- Keep hands busy and mind engaged. People are disengaged if they are not being included in the conversation or if the subject is beyond them or of no interest.

Sometimes grooves can be very beneficial, especially when combined with visuals like a checklist or calendar. You might establish a visual checklist for completing household chores, personal hygiene, or eating healthy foods.

Self-Talk or Imaginary friends

Often this is misunderstood as a mental health problem. For the person with Down syndrome it could be thinking out loud, processing events of the day, or planning ahead for the week or month. For many, self-talk is easier to understand than their conversations.

Is self-talk frequent for your sibling?

Have your parents established any rules around self-talk, such as only doing it at home, or never at work?

When to be concerned

If there is a change in quality or an increase in the quantity of self-talk, it could indicate stress or depression.

Eavesdrop! If it becomes mean or belittling, has an angry tone, contains phrases like "you are stupid" or "leave me alone" your sibling could be processing an actual negative experience. This could have occurred recently or the distant past.

Look for other signs of depression:

- Loss of interest in things she used to love.
- Change in sleep patterns, loss of appetite, vitality.
- Increase in irritability, avoidance of situations, or being unwilling to leave the house.

Has your sibling ever been seen by a psychologist or social worker? Who would your parents recommend?

Use the Daily Routine page to record your sibling's typical day. Does he need visual cues or picture cards to remind him?

Is it Alzheimer's Disease?

When there is a decline that is recognized, look for potentially reversible or treatable causes first. While there is not currently a cure if the diagnosis is Alzheimer's disease, there are medications and therapies which may be prescribed to improve function, slow the decline or treat associated health problems. Some medical practitioners are quick to blame Alzheimer's disease for a decline in daily living skills and psychological changes, when the real source might be depression or another medical or psychological disorder. *Alzheimer's disease is also one of the most commonly diagnosed and misdiagnosed mental disorders in adults with Down syndrome.*

For this reason it is important to have a complete physical in order to rule out other medical conditions before beginning treatment for Alzheimer's disease.

Symptoms to look for:

- Forgetting details (i.e. where you are going? why?)
- Losing things
- Not recognizing familiar people
- Decreased ability to follow directions
- More withdrawn, more fearful
- Loss of inhibition
- Change in sleep patterns
- Decreased speech, articulation, word retrieval
- Takes longer to eat, decreased appetite, weight loss

While the life expectancy for persons with Down syndrome has risen over the last decade and many are living well into their 50s and 60s, it is still shorter than in persons without Down syndrome. In addition, adults with Down syndrome do seem to develop some health conditions at a younger age. When adults with Down syndrome develop Alzheimer's disease, it occurs on average 20 years earlier than in others. One way to look at it would be that the rate of Alzheimer's disease in patients with Down syndrome in their forties is similar to those without Down syndrome in their sixties.

As there may be some people who fall outside the typical age range, if a person with Down syndrome declines at a younger age (e.g. age 20) it is more likely that there is an alternative explanation. Whether a decline comes early or later, since there are many conditions that can cause dementia, it is vital to thoroughly evaluate and rule out other health issues when a decline in skills is first noted. Careful assessment, support, observation over time, and treatment of any potentially reversible conditions will often help make the diagnosis more clear and lead to improvement in those individuals who don't have Alzheimer's disease. Other causes of decline in skills and memory may include:

- Depression
- Sleep apnea
- Thyroid disease
- Vitamin B12 deficiency
- Metabolic diseases (kidney, diabetes)
- Celiac disease

Psychosocial/emotional issues common to people with Down syndrome

- Loss of hearing or vision
- Atlanto-axial instability
- Seizure disorder
- Medication side effects
- Undiagnosed pain

There are many laboratory and physical tests that can help evaluate adult patients who are experiencing a decline in function. Neuropsychological tests that are typically performed when evaluating for Alzheimer's disease are more difficult for persons with Down syndrome and other intellectual disabilities, thereby making them less accurate. There are some neuropsychological tests that are designed for persons with intellectual disabilities that can provide better information. In addition, it can be very helpful to gather extensive information from caregivers regarding the losses over time, environmental stressors, and other symptoms.

If your parents have not had a baseline assessment performed for your sibling do it now. Visit <http://aadmd.org/ntq/screening> for more information.

