



# CAREGIVING TOOLKIT

Supplemental worksheets for the  
Caregiving & Down Syndrome Guidebook

## Tools for Caregivers of Adults Aging with Down Syndrome

This Toolkit is a companion resource to the *Caregiving and Down Syndrome Guidebook* to help you start planning for the future of your loved one with Down syndrome and also caring for yourself. These templates are intended to serve as a starting point for the planning process, allowing you to include any other documents or information you believe are important.



### EMERGENCY PLANNING

Emergency planning is crucial for individuals with Down syndrome, as it ensures their specific needs are met during unexpected situations. By preparing ahead of time, caregivers can provide reassurance and support, helping loved ones feel safe and prepared in times of crisis.



### SUPPORT PLANNING

Support planning for a loved one with Down syndrome is essential to ensure their long-term well-being and independence. By outlining goals, support systems, and resources, families can help create a fulfilling and secure future tailored to their loved one's unique needs and aspirations.



### SELF-CARE FOR CAREGIVERS

Self-care is essential for caregivers, as it helps prevent burnout and maintains your overall well-being. By taking time for yourself, caregivers can recharge, leading to more effective and compassionate support for your loved ones.



# EMERGENCY PLANNING

## IN CASE OF EMERGENCY CALL 911

### Police Non-Emergency Line:

Telephone: \_\_\_\_\_

Address: \_\_\_\_\_

### Personal Information:

Name: \_\_\_\_\_

Nickname: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

State ID or Driver's License Number: \_\_\_\_\_

### Information Emergency Services Should Know:

Allergies: \_\_\_\_\_

Preferred Language: \_\_\_\_\_

Communication: \_\_\_\_\_

Fears: \_\_\_\_\_

Other: \_\_\_\_\_



# EMERGENCY PLANNING

## Emergency Contact

Name: \_\_\_\_\_  
Telephone: \_\_\_\_\_  
Address: \_\_\_\_\_  
Relationship: \_\_\_\_\_

## Emergency Contact

Name: \_\_\_\_\_  
Telephone: \_\_\_\_\_  
Address: \_\_\_\_\_  
Relationship: \_\_\_\_\_

## Insurance Information

Insurance Company Name: \_\_\_\_\_  
Policy Number: \_\_\_\_\_  
Primary Insurance Holder: \_\_\_\_\_  
Group Number: \_\_\_\_\_

## Secondary Insurance Information

Insurance Company Name: \_\_\_\_\_  
Policy Number: \_\_\_\_\_  
Primary Insurance Holder: \_\_\_\_\_  
Group Number: \_\_\_\_\_

## Additional Contacts

**Primary Care Physician Name:** \_\_\_\_\_  
Telephone: \_\_\_\_\_  
Email: \_\_\_\_\_

**Dentist Name:** \_\_\_\_\_  
Telephone: \_\_\_\_\_  
Email: \_\_\_\_\_



# SUPPORT SYSTEM

It is crucial to have a team to help support you and your loved one. You can reach out to friends, family members, neighbors, community support groups, or even local affiliates or organizations. List people who are on your team and can provide support when needed. This can also include anyone involved in decision making. It is also important to clearly communicate your needs and expectations with your team to ensure that everyone is prepared and willing to step in when necessary.

## Team Member

Name:

Telephone:

Email:

Relationship:

## Team Member

Name:

Telephone:

Email:

Relationship:

## Team Member

Name:

Telephone:

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Relationship:

## Team Member

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Telephone:

Email:

Relationship:

## Team Member

Name:

Telephone:

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Relationship:

## Team Member

Name:

Telephone:

Email:

Relationship:

# SUPPORT PLAN

A support plan can be described as a blueprint for how to care for an adult with Down syndrome as their needs become more complex. This process-oriented approach can include person-centered plans, navigating daily routines, and identifying future guardians and health advocates for the individual with Down syndrome. This plan will help guide future caregivers to care for your loved one, so you can complete it on your own or with your loved one, however, including your loved one can empower them to have a voice in shaping their future.

## A. LETTER OF INTENT

A letter of intent is a tool to guide others to support the care recipient in the way both you and the care recipient desire. This letter paints a picture of your loved one's life today and desires for the future.

The Special Needs Alliance, an organization that empowers people with disabilities and their families through expert legal planning and advocacy, recommends focusing on the following areas to highlight in the letter of intent. You know your loved one best. What is unique and important to them? What do you want others to know?

**General Overview:** Provide a short overview about your loved one's life and your general hopes for their future.

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**Family History:** Share about your family life and important stories you want your loved one to know and remember.

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**Education:** What does education currently look like for your loved one? What are ways you want your loved one to be a lifelong learner?

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**Employment:** Describe your loved one's current employment status. What do you hope employment looks like for them in the future?

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**Healthy Lifestyle:** How do you want your loved one to stay healthy? Do you have goals related to their physical activity? Balanced nutrition? Emotional wellness?

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**Behavior Management:** Are there any behaviors that are unique to your loved one? What are ways you support your loved one's behavior? This could be in relation to food, hygiene, or other daily activities. Does your loved one receive behavior support through any programs?

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**Identify Advocates and Guardians:** Who in your loved one's life can advocate for them in all areas of life? Each state varies in how they view guardianship, and it important to check what the guidelines are in your state.

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**Final Arrangements:** Describe what you would like your loved one's final arrangements to look like. Please refer to the NDSS *End-of-Life Guidebook* for more support on this topic.

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**Other:** Is there any other information that is important to highlight about your loved one?

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## B. ROUTINE

# DAILY

A vertical stack of eight stylized train cars on tracks. The top car is white with a red dot, and the others are white with a black dot. The tracks are represented by horizontal lines.

# MONTHLY

1. *Journal of the American Medical Association*, 2000; 283: 2689-2693.

**MON**

**TUES**

WED

**THURS**

**FRI**

10 of 10

1000000

1000000

10 of 10

**SAT &  
SUN**

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# C. MEDICAL CARE

**Medical History:** Describe your loved one’s medical history.

**Surgical History:** List any surgeries or procedures your loved one has had.

Date	Surgery	Surgeon

**Medication History:** List current and past prescriptions for your loved one. You can also note any adverse effects from medications.

Name of Medication	Date Filled	Dosage	Prescribing Doctor	Notes

## CURRENT PROVIDERS

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This can include physicians, therapists, caseworkers, and other service providers.

### Provider Information

Name:

Telephone:

Email:

Specialty:

### Provider Information

Name:

Telephone:

Email:

Specialty:

### Provider Information

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# SELF-CARE FOR THE CAREGIVER

Being a caregiver involves love, great joy, a myriad of challenges, and sometimes even heartbreak. It is not a vocation so much as it is a labor of love; a commitment to ensuring the well-being of another. Due to the stressful and continuous nature of caregiving, those who provide care for someone with Down syndrome as they age must practice self-care.

## PILLARS OF HEALTH

### NUTRITION

Balanced nutrition is essential for overall health, enhancing mood, and boosting energy levels.



### SLEEP

Sleep is vital for overall health but particularly important for managing stress and emotions.



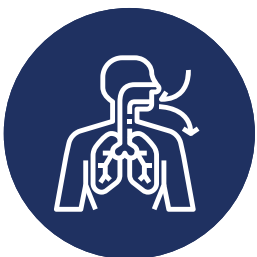
### MOVEMENT

Movement keeps your heart and muscles strong, your brain healthy, and improves your mood.



### BREATH

Using your breath is a great way to manage stress and feel more relaxed.



### HYDRATION

Staying hydrated helps increase focus, assists with digestion, and supports your body's movement.





# SELF-CARE PLAN

Pick one pillar of health to focus on first:

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How do you plan to work on this pillar of health? What is one small thing you can commit to everyday? When will you do it?

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Who can help you achieve your goals? What support do you need? A nutritionist? A movement partner? Someone to help with your loved one?

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## THINKING POSITIVE THOUGHTS

Positive affirmations can help manage stress by reinforcing a resilient mindset, boosting self-confidence, and encouraging a more optimistic perspective in challenging situations.

**I AM...**



**A GOOD  
CAREGIVER  
CAPABLE  
VALUABLE  
IMPORTANT**

## **321go!** BREATHING WITH A STRESS BALL

**Practice for at least  
one minute**



1. Inhale deeply for the count of 3 while squeezing the stress ball.
2. Hold for a count of 3 while keeping the ball squeezed.
3. Exhale for the count of 3 while slowly releasing the pressure on the stress ball.