

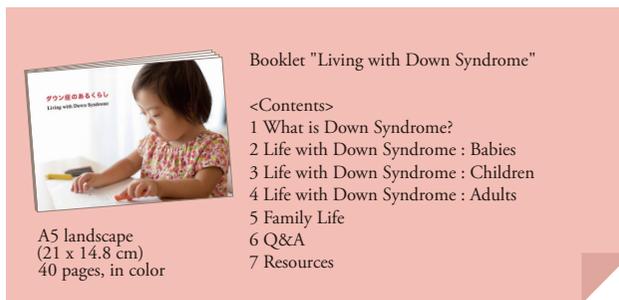
"It was scary because we didn't know."  
This booklet was developed in response to families recalling their experiences.

## ダウン症のある暮らし Living with Down Syndrome

This leaflet  
introduces the  
booklet  
"Living with  
Down syndrome"



We created a booklet describing how babies with Down syndrome grow and what lives of people with Down syndrome and their families are like in Japan. We hope this booklet will help you take a step toward knowing more about living with Down syndrome.



Booklet "Living with Down Syndrome"

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- 1 What is Down Syndrome?
  - 2 Life with Down Syndrome : Babies
  - 3 Life with Down Syndrome : Children
  - 4 Life with Down Syndrome : Adults
  - 5 Family Life
  - 6 Q&A
  - 7 Resources

## Reader Reviews

### ***Covers all the information people are looking for***

This easy-to-follow booklet describes the life of children with Down syndrome and their future prospect. New parents are surely looking for such information after receiving the diagnosis. Well-balanced, heart-warming, and beautiful. I hope this booklet reaches many people. (An obstetrician)

### ***Useful for healthcare professionals as well as parents***

This booklet will offer valuable support for parents, explaining what the life with their baby might be like and serving as a reference for them and for those around them. Also useful for healthcare professionals to check what they need to know and what they need to communicate to families. (A pediatrician)

### ***Great book to re-read at any crossroad***

This booklet contains all the information I have collected over the past three months from the Internet and word of mouth. If I had read the booklet earlier, my initial painful feelings might not have been as excruciating. I'd like to re-read this booklet when starting early childhood intervention, thinking about schooling options, and being concerned about siblings. It is then I'm sure that I will fully appreciate its value. (A mother of 3-month-old boy)

### ***A truly wonderful book***

Every life is precious, and we live with our families one day at a time. Not only the child with Down syndrome but all family members are in smile. Their days are not particularly filled with unhappiness but rather are no different from before. Their lives are just as ordinary and precious. I was moved by abundant messages each photo conveys. I know I will re-read this over and over for moral support. (A mother of 5-month-old boy)

## How to order

The booklet is available for anyone to order. Contact us below including the number of copies, your name, contact information (e-mail address) and shipping address. Yokohama Project will get back to you.

### **E-mail : [info@yokohamapj.org](mailto:info@yokohamapj.org)**

Make sure your spam filter is set to allow emails from "@yokohamapj.org" domain.

**¥500 per copy (plus shipping)**

The booklets are made available free of charge to (in Japan only) :  
(1) healthcare facilities (such as women's clinics, pediatric practices, institutions providing welfare and social services) for distribution to expecting parents with or possibly with a baby with Down syndrome, or new parents of a baby with Down syndrome,  
(2) public institutions for use as a publicly available reference, and  
(3) support groups such as parent organizations for use as a shared reference among members (limit two copies per organization).

**For further information:** please contact [info@yokohamapj.org](mailto:info@yokohamapj.org)

### **Support Yokohama Project**

We are asking for donations to continue publication of this booklet. If you would like to donate, the account details are as follows;  
Japan Post Bank (Yucho Bank) Branch Name/Branch Cord 028  
Account number 4707068  
(Donations in units of 500 yen are appreciated.)

### **What is Yokohama Project?**

Yokohama Project is an advocacy group that embraces the concept of "diversity." It was established after organizing a walking event to socialize with individuals with Down syndrome. Based in Yokohama, our group aims to create a society where everyone, with or without disabilities, affirms each other and contributes in his or her own way, ultimately leading to a resilient society that can turn adversity into progress.

HP <http://yokohamapj.org/>

f <https://facebook.com/yokohama.project>



### What is Down Syndrome?

Human body cells have 23 pairs of chromosomes, for a total of 46. Down syndrome is a condition caused by having an extra copy of chromosome 21, resulting in three copies of chromosome 21 instead of two. The name Down comes from the physician who first described the condition. The mechanisms causing three copies of chromosome 21 are still unknown. Approximately one in 1,000 babies reportedly have this condition, consistently across countries and ethnic groups. There is no difference in incidence between males and females.

### How do babies with Down syndrome grow?

### What is their life like?

This booklet provides an overview from babyhood to adulthood with photos.

(The following are excerpts from the booklet.)

### Q & A



Q. My baby has Down syndrome. Can I continue to work?

A. It used to be difficult for mothers to return to their jobs after having a baby, particularly if the baby had Down syndrome. But things have changed along with societal changes, and currently many families have two working parents. Many mothers continue to work without giving up their career after having a baby with Down syndrome. Of course, some mothers choose to leave their jobs or change their working style. They are making choices that best suit their family situation and their way of life.

The booklet contains answers to some concerns you may have but don't know who to ask, such as "Can I raise my baby?" "Should I explain my child's disability to people around me?" "What is their life expectancy?" and "Is there any public support?"

### Life with Down Syndrome : Babies

Babies sleep, wake up, drink milk, poop...and repeat. This is the same with or without Down syndrome. Only your baby may have conditions that will require medical attention, may have difficulties with breastfeeding and bottle feeding, or may grow more slowly than typical. At first you may worry and feel anxious, but over time, you will learn to cope with these differences naturally, which will gradually make you feel less burdensome.

### Life with Down Syndrome : Children

After preschool, they attend elementary and middle school. They have three choices - regular class, special needs class in a local mainstream school, or special needs education school. After school, they may take lessons in music, dance, or swimming, or stay at home with their siblings or friends. In high school, they tend to spend less time with parents and more time alone or with friends or support service staff - not only when going to and coming back from school, but also when taking lessons after school, shopping, or hairdressing.

### Life with Down Syndrome : Adults

In adulthood, their focus of life shifts from school to other locations such as workplace or day care centers for adults with disability. Today, an increasing number of small group homes are gradually being established to help individuals live more independently in the community, and more adults with Down syndrome are starting to live away from their parents at a younger age. After high school, some work for a company, at an assisted institution for people with disabilities who hope to be employed by a company, or at a workplace provided through social services. Some go to college with programs for students with learning difficulties and disabilities.

