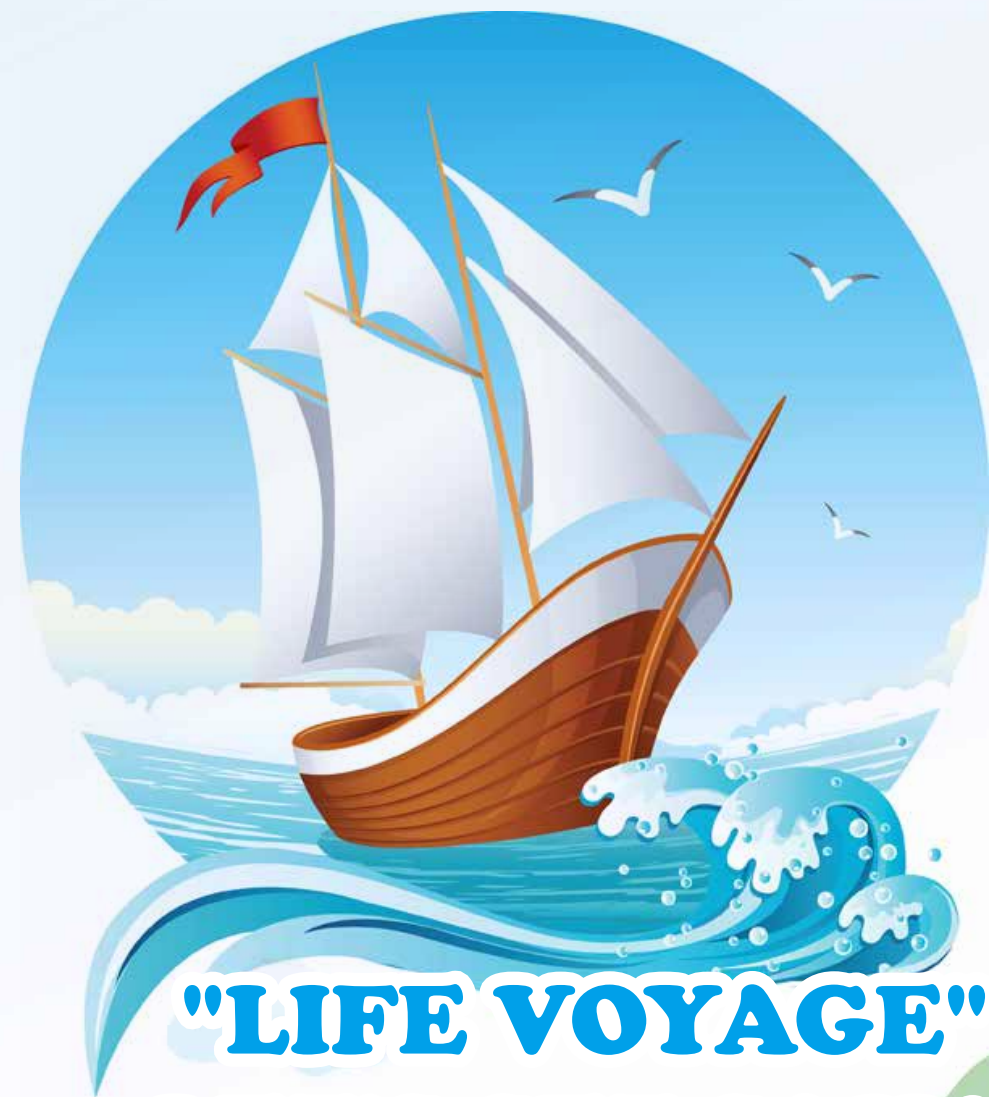




香港唐氏綜合症協會

The Hong Kong Down Syndrome Association



"LIFE VOYAGE"
LET'S SET SAIL!



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Preface

Life voyage, we walk hand in hand.
Let's set sail together.
You are not alone.
We are big 'family'.

Embracing the spirit of Santa Claus, with hope, blessing and love, we started our SweetieLand Project in 2013 and walk through the life voyage with the families. SweetieLand Project is a pioneer project of The Hong Kong Down Syndrome Association, providing early intervention and pre-school training to the babies with Down Syndrome as well as supporting their parents. Our deepest thank-you to the funding support of Operation Santa Claus for granting us 2-year project funding. Heartfelt appreciation for the parents' contribution in the production of this booklet.

When parents know their baby diagnosed of Down Syndrome, that moment is like a thunderstorm. They experience sadness, anger, guilt, grief and worries. Hence, we start to reach out the parents since pre-natal examination, engage them in our programs and provide different training to equip them knowledge and skills of child rearing. Also to grasp the golden period of learning, we arrange the children to receive individual training on various aspects, including motor skills, cognitive and language development, self care, social interaction and other special educational needs. Moreover, parent-child training group is arranged to enhance the interaction and emotions expression among the children and parents. Parents can also share their child rearing experience and express their feelings in a casual way. They meet parents with similar background and establish mutual support.

Before the Journey Start...

In this booklet, we are inspired by the stories and experiences shared by the parents. I believe their sincere sharing and valuable tips are helpful to the readers. Without their contribution, the contents of this booklet can't be so rich or fruitful. Thank you so much!

Last but not the least, I genuinely express my blessing to the children with Down Syndrome. I believe in their potentials to grow, learn and achieve a fully wonderful life. They are all unique and precious! Let's us sail and walk through the life voyage hand in hand! We are a big 'family'.

By Maggie YEUNG P.M.

The Hong Kong Down Syndrome Association
Director



The moment when babies are born, their parents embark on a "Life Voyage" together with them. To parents, no matter how hard it is, this miraculous journey is worthwhile because it is always full of hope and joy. They expect their children to grow up healthily and to fulfill the dreams they have for them. However, sudden news comes at this time of happiness....being informed that their child has Down Syndrome immediately melts away their joy of welcoming a new life. With the loss of the healthy baby they have been anticipating and holding this newborn whom they know really belongs to them, yet with so much unknown, the feelings of shock, heartbreak, despair, disappointment, anxiety, helplessness fill up their hearts. From that moment onwards, parents of babies with Down Syndrome embark on a totally different journey.

As it is a different journey, parents need navigators to help them steer along every stage of this completely diverse trip. Throughout this new voyage, we would like to be your navigators to help you stabilize your ship which is boarding a newborn baby with Down Syndrome. We will listen and try to pacify your perplexed mind, teaching you different skills for this particular navigation. At the same time, we will meet other travelers on this journey who also have children with Down Syndrome. We can then share our precious experience of laughter and tears with each other.

We can also learn to adjust our expectation for our children and to accept that they are unique. This would definitely help them to live better in future.

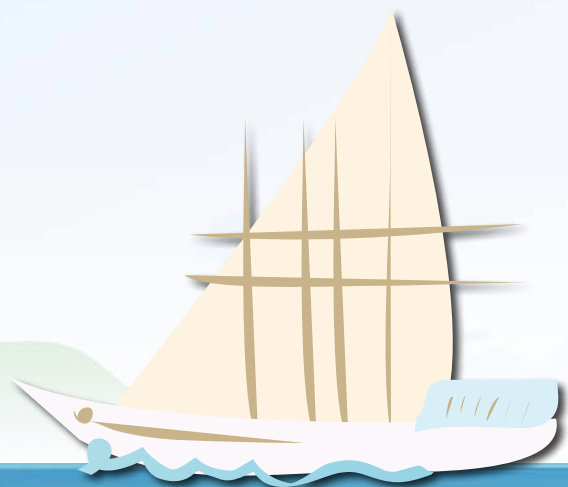
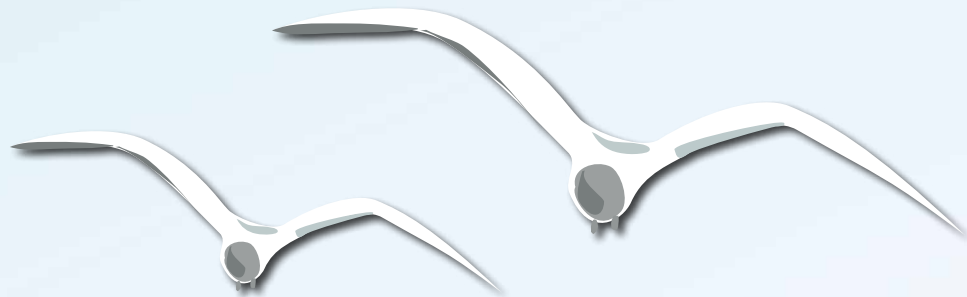
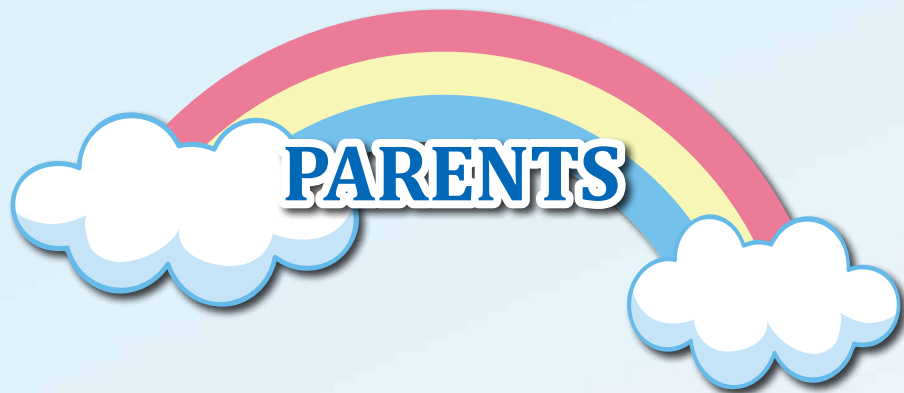
Remember you are not alone!

You are just walking a path that is different from most parents.

Remember you have us to assist you in your journey.

Together let us hold steadfastly the direction of our navigation. We can then lead our children on this journey to a healthy and happy life.

"LIFE VOYAGE" LET'S SET SAIL!



Parents

It is hard to accept at the very first moment when parents realize that their children have Down Syndrome, especially when they have been waiting for a newborn healthy baby. As mentioned, complex emotions such as shock, denial, anger, despair, guilt, heartbreak, helplessness come with the unexpected news. These emotions come and go repeatedly for a long time.

Please take a deep breath and accept your emotion. In such an unfamiliar journey, if you are afraid or tired, do quietly lie down and rest. If you want to blame or accuse, just vent your feelings out. If you feel lost or mentally disorientated, please tell us bit by bit. We are always here to listen, to keep you company, and to walk with you. When you feel better and are once again prepared, we can continue with our "Life Voyage" together. All these interwoven storms of your emotions will enable you to confirm the direction of your navigation more. Grasping and then adjusting your expectation of your children, you can then control your unique role as parents of children with Down Syndrome. Again, let "Life Voyage" sails forward!



Did you have these emotions or reactions?

Sense of guilt

"It is all my fault that I have not done chorionic villus sampling or amniocentesis. Otherwise, I would not have delivered a baby with Down Syndrome."

Remember:

If blood test comes back normal, usually an expectant mother would not consider chorionic villus sampling or amniocentesis. Therefore, it is not your mistake. The most important point is to look forward. Definitely, it is not fair to look back and judge anyone on his/ her behavior and decision in the past.

Refusal to accept

" My kid is normal. He/she is no different from other kids." Or
" He/ she is not my kid."

Remember:

It is normal to have this thought. It is really not easy to accept a child who is far from your expectation. Therefore, you do not need to think yourself strange or hideous because of this kind of thought. Also, you do not need to force yourself to wholly accept your child instantly. You should allow yourself to share any thoughts deep inside you with others as it will lead you to adjust your emotions gradually.

Doubt yourself

"What have I done wrong? So why do I have a baby with Down Syndrome?"

Remember:

Newborns with Down Syndrome occur due to genetic chromosome abnormality. It is not your fault or anybody's fault.

Worries and anxiety

"Does taking care of a child with Down Syndrome affect the family seriously? Can the child eventually take care of him/herself?"

Remember:

Undoubtedly, children with Down Syndrome will need extra patience and training from their parents. But with appropriate training, they mostly grow up being able to take care of themselves.

Suicidal thoughts

"I am full of fear when I look at my kid. I have even thought of killing my kid or myself."

Remember:

Fear comes from not fully understanding how Down Syndrome will affect the child's growth, and the impact on the family. Support from fellow parents who share their parenting experience can give you a better picture of what to expect. Moreover, you can seek help from clinical psychologists, or social workers to help you manage the negative emotions.

How to manage grief

Don't: isolate yourself, doubt yourself or harbour negative thoughts

Do: Understand that your emotional response is normal, natural and common, share your concerns with friends and family or professionals

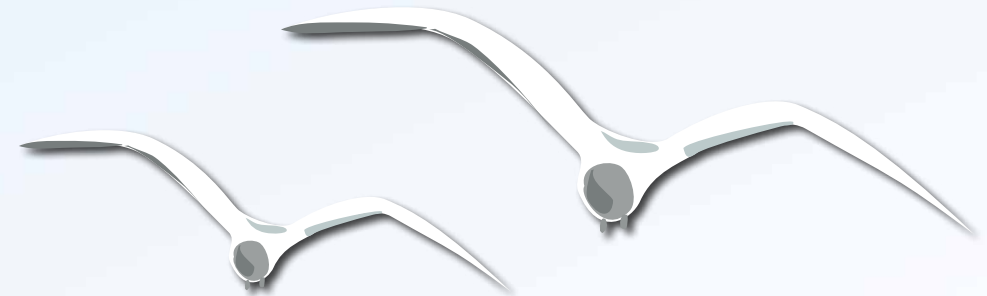
When we face a serious setback or disappointment, it is very normal to have negative emotions. Therefore, we do not need to blame ourselves, or even doubt your abilities or attitudes as parents. Parents can talk with trusted relatives or friends to vent your emotions deep inside. If negative emotions persist, please seek help from clinical psychologists, counsellor or social workers. In addition, parent groups of The Hong Kong Down Syndrome Association are ready and willing to share their stories with you which is effective mutual support.

When to break the news?

Should I tell relatives? When should I tell them? Many parents struggle over when or how to break the news. There is no golden rule. But when you have come to terms with the situation, then it would be a suitable time.

It is foreseeable that friends and relatives would have different sorts of emotional response or doubts when they learn that your child has Down Syndrome. This applies especially to grandparents who feel very close to the newborn. They would need time to adjust and accept. In this process, they might be prompted by their confusion and sadness to raise many questions regarding the causes of Down Syndrome. They might link the cause to the health of the parents, or their activities. Parents should bear in mind that their relatives' concerns are not meant to be accusations. Such reactions are natural when they go through different stages of overcoming their sadness. Therefore, parents need to be prepared themselves emotionally to help their relatives adjust and accept. Do give each other breathing space and time as this is indeed a situation totally unexpected.

When parents are ready to face their situation graciously and with an open mind, they will be able to understand and communicate with their friends and family. Sharing and honest exchange of feelings will lead to deeper bonding amongst family members.



Understanding

After reading the previous sections, we hope that grief and worries of parents can be relieved to some extent and their emotions will gradually stabilize. Sadness may still linger on, and it may still be hard to accept the reality. We know that this “Life Voyage” is a very long journey. Raising children is not easy, especially children with Down Syndrome. There is no need to worry. You are not alone. Let us learn more about Down Syndrome and prepare to embrace the challenges encountered in the growth and development of our baby with Down Syndrome.

What is Down Syndrome?

The cause of Down Syndrome is still unknown up to this date. But one thing certain is that no parents or individuals should take the blame. Down Syndrome is a genetic disorder of DNA, so it is no one's fault. There are 23 pairs of chromosomes, that is a total of 46, in each human cell. However, the cell of a person with Down Syndrome has an extra chromosome in the 21st pair, meaning there is a total of 47 chromosomes.

What is the chance of having Down Syndrome?

In Hong Kong, there is approximately 1 baby with Down Syndrome in every 800 newborn babies. No evidence has been found that any country or race has a higher incidence of Down Syndrome in babies being born.

Can Down Syndrome be cured?

Down Syndrome is caused by irregularity in the chromosomes of the human cell. It is not an illness. Therefore, it cannot be cured by medicine or surgery.

What are the characteristics of a person with Down Syndrome?

Most people with Down Syndrome have similarities in their appearance as they all have the same extra chromosome. They also share similarities in their physical and intellectual development, and medical complications.

Appearance	Health
<ul style="list-style-type: none">● Broad head or round face● Crossed-eyes● Flat nasal bridge● Small mouth● Low muscle tone● Tongue with coarse grain● Short fingers● Excessive space between large toe and second toe● Short stature	<ul style="list-style-type: none">● Slower growth● Low muscle tone● Congenital heart disease (40%-60%)● Visual impairment● Hearing impairment(40%-60%)● Thyroid dysfunctions (10%-20%)● Cervical vertebra dislocation (10%)● Sleep apnea● Obesity (50%)● Dementia (Alzheimer's disease)
Intelligence	Personality
<ul style="list-style-type: none">● Low cognitive function● Mild or moderate mental retardation (80%-85%)● Delay in Learning	<ul style="list-style-type: none">● Optimism● Friendly● Honesty● Stubborn● Love music and dance● Like to imitate others

However, the above are just generalized descriptions while the fact remains that every person is unique, including a person with Down Syndrome. Therefore not everyone with Down Syndrome has these characteristics.

What difficulties does a baby with Down Syndrome face?

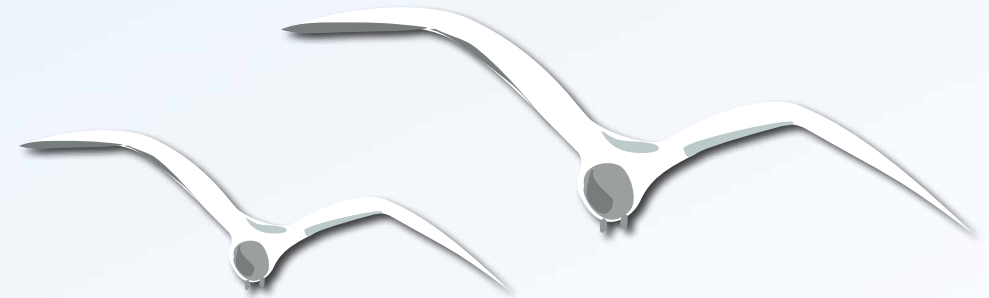
- Low muscle tone
- Lack persistent muscle strength
- Loose joints
- Deformed joints
- Weak eye-hand coordination
- Weak cardiopulmonary function
- Learning disability

For consultation on the above problems, you can approach physiotherapists, occupational therapists, or special education teachers with training in early childhood education. With training and therapy, improvement is attainable. Training should start as early as possible for the best results.

What are the developmental needs of a person with Down Syndrome?

People with Down Syndrome have different developmental needs at different stages. Caregivers should have knowledge of these needs and seek various appropriate services to help them overcome obstacles they may face as they grow up. The prime objective is to train them towards independence and social integration. Please refer to the table below for reference.

0-5 years	6-17 years	18 years or above
<ul style="list-style-type: none">● Early training● Physiotherapy● Sensory training● Health checking● Self-care training	<ul style="list-style-type: none">● Special / integrated education● Self-care training● Social manner & etiquette training● Sex education● Hobbies development● Health checking	<ul style="list-style-type: none">● Occupational training● On-job training● Social intercourse / independence● Sex education (love, sexual needs, marriage)● Hobbies development● Health checking



Caregiving

Now we have arrived at the station of Caregiving of “Life Voyage”. You must have a lot of worries over how to take care of the baby. Would I hurt his/her soft body and unsteady neck? Why does my baby always stick out his/her tongue and take so long in sucking milk? Will my baby be able to take care of him/herself one day? Can this baby talk, walk or be independent? I have other children beside my baby with Down Syndrome. How do I help them to accept and love each other?

Questions are numerous, but what is certain is that the earlier you establish good habits, the easier it is for you and your child to acquire the needed abilities and techniques to overcome challenges. In “Life Voyage”, there are five beacon lights to help you navigate on the right course: physiotherapists, occupational therapists, speech therapists, qualified special education teachers, and social workers. They can assist you to overcome the challenges along the journey.

Health

The body of a baby with Down Syndrome is generally rather soft due to low muscle tone and loose ligament around joints. For example, the mouth, neck and elbow areas are softer than normal, and are especially noticeable when the babies are sleeping or sitting. Parents are always afraid of hurting their babies because they are as soft as cotton candy. Due to weak facial muscles, babies may stick their tongue out with their mouth open wide. Their neck and legs have so little strength, so that parents really do not know how to hold the baby up. Actually, parents do not need to worry, as these conditions would improve as their baby grows up. Further progress is attainable with continuous training. Therefore, parents should apply for physiotherapy or occupational therapy as early as possible from hospitals or organizations that provide such services so their baby can receive training. Parents can also learn how to train the baby at home. This will help to improve the coordination and balance of the baby.

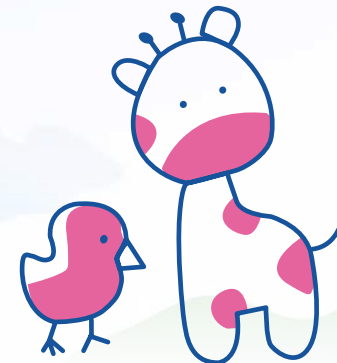
Tips from “Voyage Partner”

Feeding

The sucking ability of a baby with Down Syndrome is affected by the relatively poorer control of mouth and tongue muscles due to low muscle tone. Therefore, besides consulting professionals, parents must be psychologically prepared for a longer feeding time. The feeder should find a comfortable place to sit with support, so the caregiver and your baby can be relaxed during feeding time.

Gross and Fine Motor Skill Training

Children discover new things everyday, and so do babies with Down Syndrome. While our children grow up, they will enjoy and benefit from playing with their parents. Even a most ordinary item or activity could be an effective teaching aid, like a piece of cookie, an empty can, simple household chores, or the small playground near your home. Parents can try to observe the techniques and skills used by therapists during therapy sessions and ask questions where needed so as to fully understand how to reinforce the training at home. You will find that many simple tasks in our daily lives are effective training for gross and fine motor skills.



Self-care

No one is born with the ability to take care of him/herself. Self-care has to be taught during childhood. Children with Down Syndrome are mentally challenged which means they would need more time to learn to sit, crawl, and walk. However, through the patience of therapists and parents and repeated opportunities to practise, they will learn basic self-care skills like going to toilet, taking a bath, brushing teeth and washing face. Parents should always remember that “Skyscrapers are built from the ground”, likewise the foundation for learning self-care should start from an early age. This secret we share really tests the efforts and determination of parents. Appropriate expectations and opportunities to practise are keys to success.

Tips from “Voyage Partner”

Establishing Habits

Parents can encourage their baby to hold the milk bottle or grab things to eat by him/herself. Tidying up toys and carrying a backpack, taking a shower with minimal help are all to be encouraged. Besides learning how to do these tasks precisely, children will form a habit of self-care, leading eventually to independence. This would make the life of parents much easier in days ahead.

Expression

Most children with Down Syndrome talk, but they would take longer to learn. With weak muscles of the mouth, their speech development is hindered. It is advisable to seek the help of speech therapists when children with Down Syndrome reach the age of when they learn how to talk. Through exercise and massage of facial and oral muscles, improved muscle tone will prevent children with Down Syndrome to stick their tongue out, and improve their ability to speak. From experience and research, children with Down Syndrome are found to have better comprehension than language expression.

Tips from “Voyage Partner”

5 Rules to Effective Speech Training

- 1) Talk to your children constantly
- 2) Enrich them with life experiences
- 3) Let children express themselves
- 4) Increase the self confidence of your children by lots of encouragement and praise
- 5) Follow the interest and ability of your children in stimulating their language ability

Social Life

A lot of people have described babies with Down Syndrome as happy and carefree, but sometimes stubborn. Are babies with Down Syndrome very difficult to look after?

Understand your child

Extensive research has concluded that there is no one unique model that encompasses the full range of characteristics of Down Syndrome. Just like other children, they experience the full range of joy, anger, misery and happiness and there are both positive and negative aspects to their personalities. For example, for a stubborn child, if the parents can channel this trait into persistence in learning and mastering a self help skill, or pursuing a hobby, their child may make good progress and achieve wonderful goals.

The key lies in understanding your child, and his or her behavior from all aspects, and train and teach your child accordingly. You can consult special education teachers, and social workers on parenting and training skills. Through participating in small group training, your child can learn to interact with peers and strengthen his or her social skills and etiquette.

Get along with other children

If you already have other children, or plan to have more children, you may worry about sibling relations. There are both rewarding and challenging experiences in sibling relations. From our experience, it is quite a challenge to take care of a child with Down Syndrome and normal children at the same time, especially when they are close in age. They would all be vying for the love and attention from their parents. It is therefore very important that children are encouraged to express their own feelings, and be made to feel that they have equal attention and treatment from their parents. While they grow up, parents should educate them on the characteristics of Down Syndrome, and provide information so they will get to understand and accept the things their parents do in raising the child with Down Syndrome.

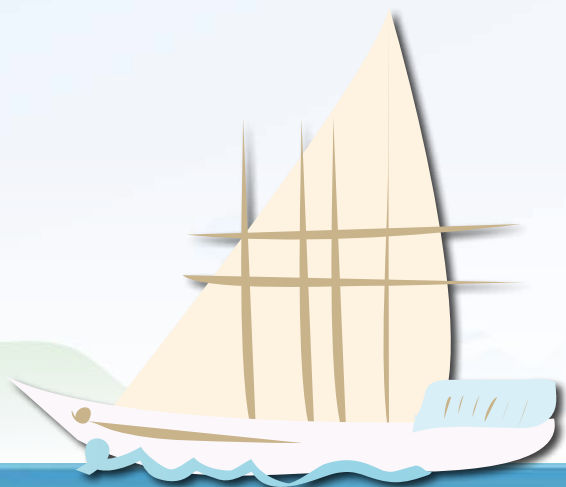
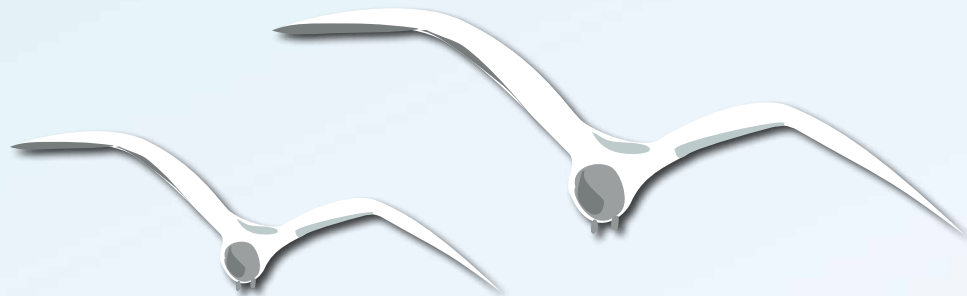
Tips from “Voyage Partner”

Learn social skills through interacting with peers

People learn from each other while they interact and socialize in a group setting. In raising children with Down Syndrome, it is most beneficial to give them opportunities to meet and interact with other children of similar age. You may wish to join “Little Sweet Heart” parent support group of The Hong Kong Down Syndrome Association, go to the park, or organize other activities to stimulate the development of your child.

The above aspects on the growth and development of a child with Down Syndrome are all inter-related. To ensure holistic development, we recommend starting with the basics, and staying in touch closely with special education teachers, social workers and other professionals so as to understand and be aware of the needs of your child, and learn the appropriate training skills. More importantly, parents and child can be compared to a two-sided mirror: you are held together tightly, and parents’ emotions and feelings affect the child and are reflected in the child directly. Even though this journey of child rearing is not smooth sailing, rest assured that we are always ready to lend a hand. Let us charge ahead courageously.





Medical

Your baby with Down Syndrome may have various health issues, but please do not worry too much. A lot of the congenital illnesses affecting the heart, thyroid function etc can be diagnosed early during infancy. With appropriate treatment, children with Down Syndrome can grow up healthily. Regular health check and assessment, or if needed, treatment, are most important. Parents should find out information on the medical services available in Hong Kong for children with Down Syndrome so their child can receive the needed treatment promptly.

How to get the most appropriate treatment for your baby?

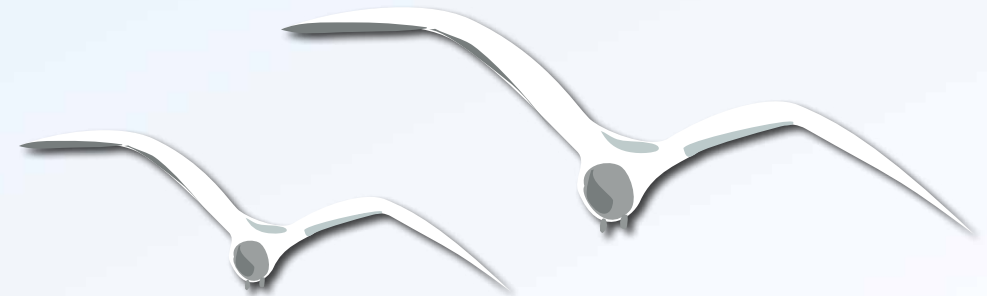
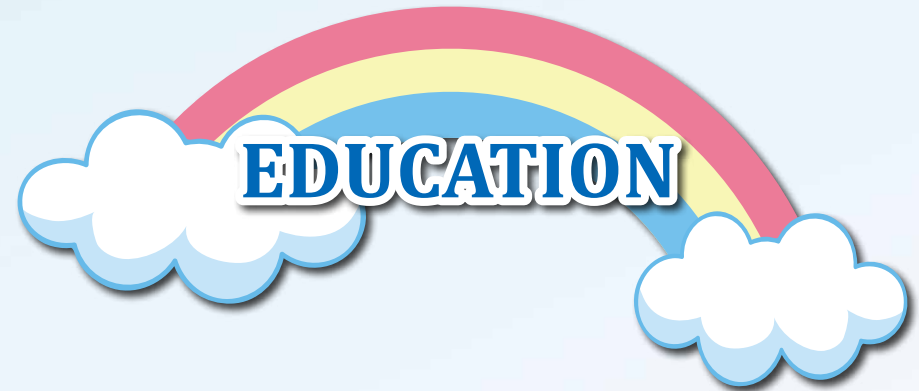
Under normal circumstances, doctors will refer your baby to physiotherapy, occupational therapy or speech therapy according to need. You are advised to communicate thoroughly with the doctor so as to get well acquainted with the condition and health of your baby. Prompt and timely treatment yields best results.



Are there specialty clinics?

Currently, there are “Down Syndrome Specialty Clinic” established in four public hospitals in Hong Kong: Caritas Medical Centre (Kowloon), Prince of Wales Hospital (Shatin), Alice Ho Miu Ling Nethersole Hospital (Tai Po) and Tuen Mun Hospital (Tuen Mun). These clinics serve patients with Down Syndrome from newborn to age 18, providing a comprehensive range of treatment. However, please note that these hospitals only accept patients who reside within their geographical regions, or are referred by doctors. You cannot apply on your own.

The Hong Kong Down Syndrome Association and Caritas Medical Centre jointly produced a “Health Care Handbook for Person with Down Syndrome” for systematic health recording. It is now adopted by the above hospitals and Kwong Wah Hospital. The Handbook is full and comprehensive, detailing all health issues of your child from birth. The Handbook is designed for all kinds of medical appointments at the hospital or other clinics for easy reference of the attending doctors. However, if your child is not a patient of these hospitals, you do not need to worry. You can obtain information on this health record by contacting us. You are also most welcome to join other parents at the “Concerned Group on Medical Services for Down Syndrome” and advocate for improvement.



Education

Before Formal Education...

As parents, you may ask, “Can my child with Down Syndrome go to school?” Actually, every child, including our children with Down Syndrome, has the right and opportunity for education.

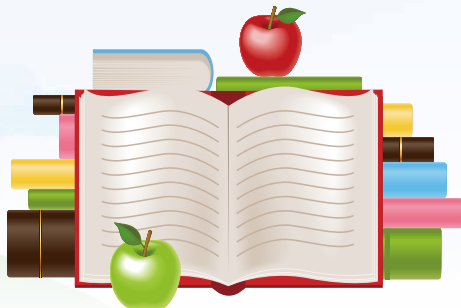
Addressing the special education and developmental needs of children with Down Syndrome, the local education system provides a series of educational services. For children aged 0 to 6 years, there are two main types of services, namely, “Training Centres”, and “Residential Centres”, both of which are under subvention of the Social Welfare Department. Medical social workers, social workers in Integrated Family Services Centres, and paediatricians are all available to provide assistance.

You may visit the website of the Social Welfare Department for more details

<http://www.swd.gov.hk>

>Public Service>Rehabilitation Services>List of Services>
Pre-school Rehabilitation Services.

*Applicants should refer to any social worker / professional that makes an application to CRSRehab on behalf you for the above services.



Early Education and Training Centre

Young children with Down Syndrome are delayed in cognitive and physical development. So it is important to start early intervention to lay a firm foundation for future progress.

The earlier you make use of the golden period of development, the better the foundation will be. It is what early intervention focuses on. In Hong Kong, there are Early Education and Training Centres (EETC), which provide early intervention training for 0 to 2 years old with developmental delay. A range of professionals are available for consultation and follow up based on different stages of development. Professionals also provide training and suggestions to parents on how to teach their children at home.

Application for EETC services are made through referral by social workers. Please be aware that it takes time. Therefore, to ensure timely treatment and education for your child, please do not delay in making the application.

Do I need to help my child apply for early intervention services?

Under normal circumstances, parents can initiate an application for EETC services on the diagnosis of Down Syndrome of his or her child through a social worker. “The first application date” is used in the queue for services. From our experience, it usually takes 1½ to 2 years.

EETC, its standardised fee is \$146 per year, if you prefer private services, the charges vary. For your consideration, this pre-school service may last for few years, the financial cost may be heavy. If parents decide to send their children to private kindergartens, EETC can provide consultative service for children until 6 years old. Among all EETCs, there are 2 EETCs providing services for English-speaking families as follow:







(see the next page...)

Early Education and Training Centre

Watchdog Early Learning and Development Centre

 G/F, 12 Borrett Road, East Wing, Central, Hong Kong
 2521 7364
 2522 0734
 info@watchdog.org.hk
 <http://www.watchdog.org.hk>
 45

The Child Development Centre at Matilda





 4/F, Prime Mansion, 183-187 Johnston Road, Wanchai
 2849 6138
 2849 6900
 info@cdchk.org
 <http://cdchk.org>
 40

Private Kindergartens(International Kindergartens)

The list below are some of the kindergartens provide English-speaking education for children with special needs. However, the kindergartens may not have specially trained teachers and parents may required to offer assistance in some cases. Places are limited. Parents are welcome to contact the kindergartens directly in order to get more information.




English Schools Foundation International Kindergarten

The English Schools Foundation organized 5 kindergartens for English-speaking children. For more details you may contact them or visit the website below:


 2574 2351
 2818 5690
 info@esfcentre.edu.hk
 <http://www.esfkindergartens.org.hk/>

Woodland Group of Pre-schools






The Woodland Group organized 11 pre-schools for English-speaking children. For more details you may contact them or visit the website below:

 2559 4855
 2559 7162
 <http://www.woodlandschools.com/>

Small World Christian Kindergarten

 No. 10, Borrett Road, Mid levels, Hong Kong
 2525 0922
 2530 5448
 office@smallworld.edu.hk
 <http://smallworld.edu.hk/>

Starters School

 1B, 1/F, Queen's Road East, Wanchai, Hong Kong
 2527 8676
 2529 9930
 info@starters.edu.hk
 <http://www.starters.edu.hk/>

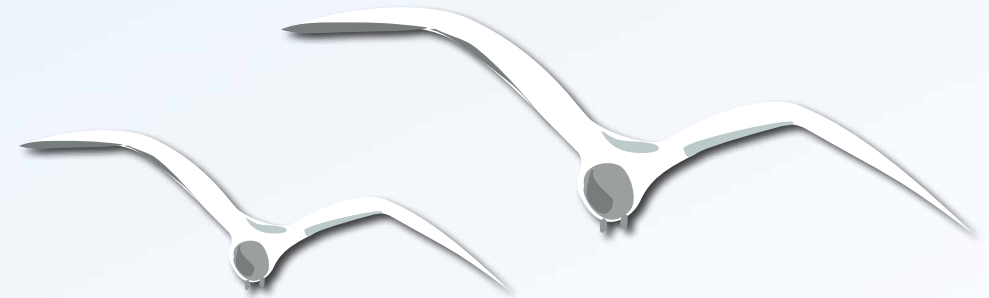
Chinese school or English school?

When parents choose a school for their child, they should consider several aspects, such as quality of teaching, school mission, the level of the children, school location and so on. For English-speaking families, the language adopted by a school would naturally be a very important concern. In Hong Kong, Chinese is the predominant language. Learning in Chinese may be an option as special schools and training services in English are very limited. However, when parents choose a Chinese school, something must be considered.

The language of teaching is different from the child's mother tongue and so there is a possibility of difficulty in communicating with parents and family. It also implies the problem of adaptation for the child. Besides, parents should think about their duration of staying in Hong Kong. All in all, parents should consider different aspects before choosing a suitable school for the child.

As children grow up and develop, they attend school and mature into adulthood. School is the best partner along this journey as it helps parents to help their children to maximize their potential. In this process, parents should make an effort to communicate with the school, so realistic expectation for their children based on their abilities could be set.

The needs of the children should be our priority and "The Life Voyage" will help them gain confidence and ascertain their self value in this journey to a happy and fulfilled life.



Financial Support

Financial burden is a practical concern since children with Down Syndrome may require a range of rehabilitation services based on their individual needs. You may worry about the family financial difficulties caused by medical expenses and various training needs. You may also want to secure financial support to raise the quality of life for the child. Actually, parents can apply for some financial support through schemes such as Disability Allowance and Community Care Fund.

How to apply for Disability Allowance?

Disability Allowance is part of the Social Security Allowance Scheme. It is granted based on the condition of disability of the child, and not the financial condition of the family.

You may apply for Disability Allowance for your child directly from Social Security Field Unit of the Social Welfare Department. Parents can also consult their child's doctor who will assess each case, and not every child with Down Syndrome is eligible. Criteria include the disability would last a minimum of 6 months, continuous care for daily routines, and not residing in government hostels, hospitals or special schools.

After consideration of different factors, eligibility will be verified. Social Security Field Units of the Social Welfare Department will issue the Normal Disability Allowance or Higher Disability Allowance. The doctor may recommend permanent Disability Allowance or Disability Allowance with an expiry date, depending on the condition of the child. If you accept the Disability Allowance with an expiry date, you will need to approach the doctor for renewal of the application upon expiry. The allowance will not be extended automatically.

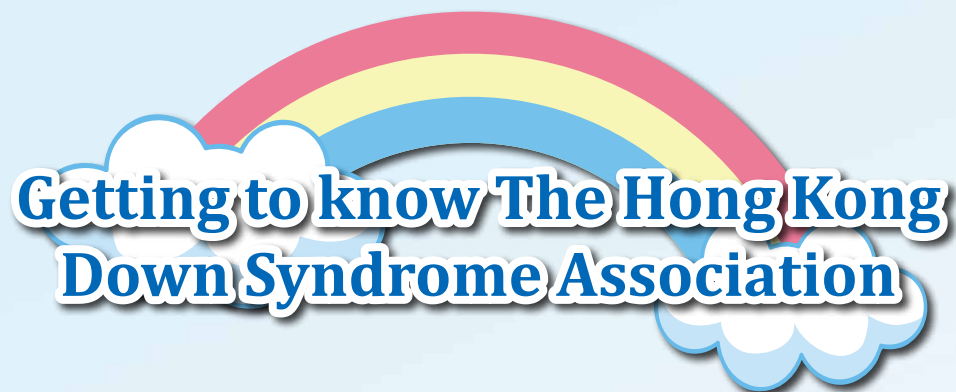
For more information: <http://www.swd.gov.hk>>Public Service > Social Security > Social Security Allowance Scheme.

How to apply for Community Care Fund?

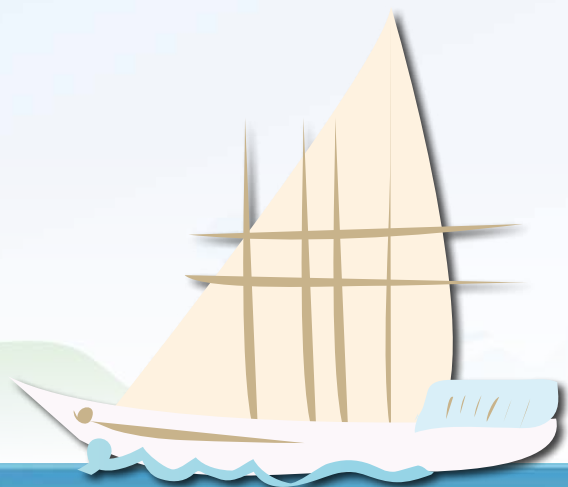
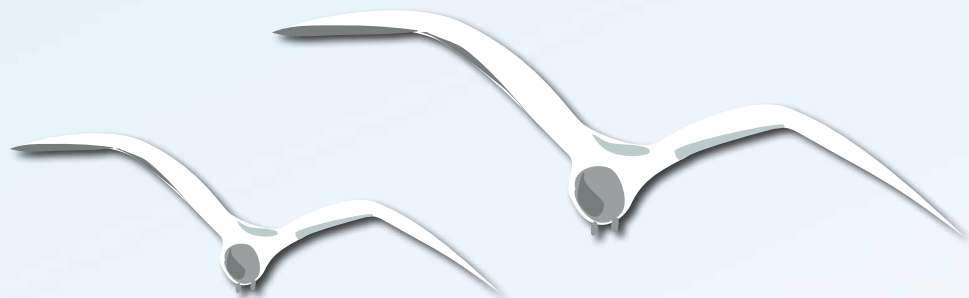
"Training Subsidy for Children who are on the Waiting List of Subvented Pre-school Rehabilitation Services", one of the Scheme of Community Care Fund, aims at providing subsidy for training for not more than 12 months for children who have rehabilitation needs in low income families. So they can receive the needed service while on the waiting list. The family income of the applicant cannot exceed 75% of the median income in Hong Kong, excluding the assets. Please check the website of the Social Welfare Department website for further information:

<http://www.swd.gov.hk> >Public Services >Support Services > Community Care Fund Assistance.





Getting to know The Hong Kong Down Syndrome Association



Getting to know The Hong Kong Down Syndrome Association

In “Life Voyage”, we face storms and challenges. Fortunately, we can seek help and support from typhoon shelters along the way. Many people with similar situations would be happy to share their experience with you, hopefully to give you respite, and recharge you with energy.

Our mission and belief

The Hong Kong Down Syndrome Association (HKDSA) was established in 1987 by a group of concerned parents of children with Down Syndrome and was registered as a charitable organization. Our services are provided to people with other disabilities as well. Our mission is to improve the quality of life of people with Down Syndrome or other disabilities and that of their family. We believe that people with disabilities are able to achieve their potentials if they are given opportunities and support in the society. They can also exercise their own decision to achieve equality. Our services include family support services, community education, advocacy, member’s developmental services and integrated occupational rehabilitation services.

We have Parents Committee and different working groups, such as “the Planning for Parents’ Training Group” and “the Rights Promotion and Policies Concern Group”. The Planning for Parents’ Training Group aims at raising parents’ knowledge and skills in taking care of children with Down Syndrome. The Rights Promotion and Policies Concern Group focuses on advancing the rights and interests of people with Down Syndrome, and makes suggestions on related policies to address the concern of parents on the issues. HKDSA maintains close and direct contact with parents and their children with Down Syndrome, and provides needed services.

HKDSA English Speaking Group

To maintain the network among the English-speaking parents, the group provides information and resources to enhance their mutual support. Parents are gathered to share the upcoming activities, parenting information and any useful resources such as medical services in the group. Counseling service is available for families in need.

☎ 2718 7776

📠 2718 0811

🏢 G/F, Wing A, Chun Tung House, Tung Tau Estate, Kowloon

✉ hkdsa@hk-dsa.org.hk

💻 www.hk-dsa.org.hk

Support service for parents of newborn babies with Down Syndrome

As the only organization focusing on people with Down Syndrome, we strive to extend support and assistance to parents who are faced with difficulties and anxiety on learning that their babies have Down Syndrome. The services below will support you in the journey of your child's "Life Voyage".

"Little Sweet Heart" Monthly Gathering

Parents of children with Down Syndrome have to deal with many aspects of childcare and will be full of questions. "Little Sweet Heart" parent support group welcomes families with children with Down Syndrome to attend talks or sharing groups held periodically so as to support each other and alleviate the anxiety in taking care of their children.

Bridging the Gap – SweetieLand

Since 2012, we have provided services by qualified special education teachers, physiotherapists and occupational therapists to children with Down Syndrome who are waiting for pre-school services. These services are made possible by the generous support of the **Operation Santa Claus**. Through individual consultation and family training groups, we can make use of this golden developmental period to help address the problems of developmental delay.

Concern Ambassador – We are on the same boat

HKDSA was founded by a group of parents whose children had Down Syndrome. We deeply share your experience. We have experience in tackling the needs and different kinds of situations encountered by children with Down Syndrome. We are also learning every day. We are not perfect but we love to share our experience with you and welcome you to share yours with us.

Counseling Service – We listen with our heart

You maybe confused and stressed when you first find out that your child has Down Syndrome. Later on, you may have a lot of questions and worries. You really have had a hard time. If you need some space, a listener, an understanding heart, or information about services, we are happy to step in to support and provide useful information. You can call the hotline of our support service for family of newborn babies with Down Syndrome to contact our social worker.

Let us support each other to explore the future.

Hotline: 2718 7777

Other Support – Hong Kong TransLingual Services

Hong Kong TransLingual Services (HKTS) is a social enterprise that provides interpretation and translation services for ethnic minorities, as well as sign language interpretation for the deaf in Hong Kong. Translation languages include Urdu, Thai, Korean, Japanese, French, German, Spanish, Sign language, etc.

☎ 2423 5101

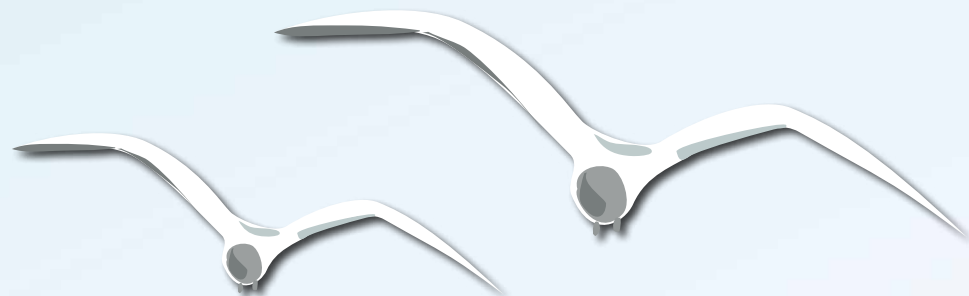
✉ hkts@hk.skhlmc.org

😊 24 hours (including public holidays)

🏢 Room 113, 1/F, 22 Wo Yi Hop Road, Kwai Chung

Reference:

1. "Little Encyclopedia About Down Syndrome", published by HKDSA, 2002
2. "Linked Heart Under the Same Roof", published by Parents' Association of Pre-school Handicapped Children, 2012
3. "Handbook of Rehabilitation Service", published by Social Welfare Department, Hong Kong, 2004
4. The website of Social Welfare Department, Hong Kong <http://www.swd.gov.hk>



Words from parents

Life is like a voyage. It is not easy to sail on the big ocean. Even more than skills, we need courage. Everything is especially difficult at the beginning. It will serve us well to be sufficiently prepared, and be steeped in hope right from the start. Let those parents who have experienced such a different voyage hold you by the hand along this journey. Let us support each other in this Life Voyage to seek a beautiful future for our children!

My Dream Girl

By Hitomi's mum

Before pregnancy, I dreamed very strange dream. A girl with Down Syndrome, around 4-5 years old, appeared in my dream. She was so cute that I asked her 'May I be your mum?' Then, I had pregnant, I could meet Hitomi. She was not only the child with Down Syndrome, but also with two diseases. Although she took surgery twice, she grew up cheerfully. She is almost 4 years old. She is so cute like the girl who was in my dream. I am proud of becoming Hitomi's mum. I have been enjoying to caring Hitomi. Don't worry! The child with Down Syndrome grows up slowly. I am sure you will enjoy raising your child!

YES WE CAN

By Sonja Shih

In 1991, when my daughter with Down Syndrome was four, we visited a cafeteria at a museum in San Jose, USA, during our family vacation, where a few young people with intellectual challenges were hired. One of them worked as a cashier. I was so impressed and excited to see how the business was run efficiently, and how the staff all looked happy and confident. I couldn't help but envisage that one day my own daughter would be able to have a job just like them. At that time, such a venture was unheard of in Hong Kong.

In 2004, when my daughter was 16, I was approached by the Integrated Vocational Training Centre of Hong Chi Association (HCA) to help set up an off-site training café for their students undergoing training in their Food and Beverage Department. Right away, the image of the café in San Jose flashed across my mind. I embraced this opportunity as I could see how it could be the beginning of the journey to realize my dream for Evelyn, my daughter.

HCA is the largest non-government organization in Hong Kong dedicated solely to serving people with mental challenges. 10 years down the road, HCA now runs a total of 6 cafes all over Hong Kong, with more in the pipeline. Young people from their training centre are placed in these cafes to gain on the job experience, and eventually placed in open employment. A team of staff at the Social Enterprise

Department of HCA oversees the management of the cafes and job placement. A contingent of some 40 volunteers, including myself, help out at various outlets during the peak hours. Caring companies in partnership with HCA to promote integrated employment include The Marriott Hotel, The Harbourview Renaissance Hotel, Langham Hotel, L'Oreal Paris, The Spaghetti House, Starbucks, MIX, Pacific Coffee, Triple O, The Hong Kong Jockey Club, Leisure and Cultural Services Department, to name a few. Employment of people with intellectual challenges has gradually gained acceptance in Hong Kong.

Evelyn is lucky to be placed in a job at a social enterprise café. Her smiling face every morning when she leaves for work says it all: Having a job is vital to one's self-esteem and well being. Having a challenge may mean you have to work harder. But it does not mean you cannot achieve your goal.

Dare to dream, and work tirelessly to realize your dream. It is possible. Finally, let me share this quote with fellow parents:

"Don't be disabled in spirit as well as physically."

By Stephen Hawking

We Could Not Without You

By Peter, Kathy, David, Matthew, Jessica, Caleb, Bethany and Abbie Lee

We adopted our daughter Abbie when she was 11 months old. We had experience caring for children with Down Syndrome previously through work and also as foster carers and we knew what a joy they can be, and how they can grow and thrive when given the opportunity and so we asked to adopt a child with Down Syndrome.

Abbie is now 2 ½ yrs old. She has brought our family more joy than we ever thought possible. She is funny, cheeky, very loving, determined. And just like other children her age she loves her family, she loves to play with her toys and she makes messes and gets up to mischief!

Although we were not around to experience her first months of life, she was still a baby when she arrived, and we have celebrated every milestone in development-even if she has reached them slightly slower than some children.

Having a child with Down Syndrome in our family has made all of us appreciate life more, to celebrate the small things, and our other children are more caring, loving, and unselfish than ever before. We couldn't imagine life without Abbie!

You are not alone!

You have us along this journey!

Let us begin the voyage together!

Guide our children towards a healthy and happy life journey!

Let "Life Voyage" set sail bravely!

Let's go Life Voyage!



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