

#### 關於我們 ABOUT US

兒童心臟基金會成立於1994年，致力服務先天性心臟病兒童及家人。基金會的服務包括提供經濟援助、贊助手術器具、購置醫療設備、安排海外醫生到訪進行醫學交流、為病童及家長提供情緒治療及心理輔導支援和定期舉辦各項教育及發展性活動等。

Children's Heart Foundation was established in 1994 to support children and their families affected by congenital heart disease. The CHF provides a wide range of services such as financial support; purchasing medical equipment; counselling, liaising with overseas surgeons; provides professional psychological counselling and therapies; and organizing regular educational and developmental and supporting programmes.

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Sharing

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(所有內容皆為中英對照。)  
(All content is written in both Chinese and English.)

## EDITOR'S NOTE 編者 ·· 的話

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從嬰兒時期呱呱落地一刻開始，我們就會經歷不少人生歷程，學習走路及說話、升學、工作等等。然而，對於不少先天性心臟病兒童來說，他們一出生可能比別人經歷多一個人生歷程—心臟手術。在成長路上，這個跟隨一輩子的疾病，亦會為他們添加不少隨時影響一生、影響生命的轉捩點。

本期《心訊》以「成長的歷程」作主題，記載了心童如何在疫症蔓延時應考公開試及報考中學，經歷這些成長的必經階段的故事。同時，在《心童有話兒》中，心童家長及青年心童透過日記、電影或劇集，分享他們過往面對疾病的心情，並如何與現在的生活作連結，並從中得到啟發。

成長路上的走向，很多時源於日常的細節。對於心童而言，家長的陪伴可以說是重要的，然而面對未知的可能，家長也會感到困惑。本期專欄由兩位不同範疇的治療師為家長「分憂」，一起學習如何提供更好的成長環境予心童。

### —— 公共傳訊事務委員會

From the moment we were born, we need to go through many stages in our lives. Learning to walk and speak, studies and work, etc. However, for those children with congenital heart disease, they may have an additional challenge in their lives - heart surgeries. It may bring many life-changing situations to the children who grow up with this congenital defects.

The title of this issue is "Milestones of Life", which tells us the story about how two of our members went through the necessary stages of growing up, taking the public examinations and applying to secondary schools during the COVID-19 epidemic. In the "Voice of Children with CHD", parents and young children share their stories of how they tackled their obstruction and gain inspiration from diaries, films or TV dramas.

Much of what goes into growing up comes from the everyday details. For children, companionship from parent is the most important thing, but parents can also be confused by the unknown possibilities. In the column parts, two therapists from different disciplines share the advices for helping parents to learn how to provide a better environment for their children to grow up in.

### —— Publicity and Publications Sub-committee

## 專題 ·· 故事 Feature Story

# 奮鬥時刻 堅持走過

## A TIME OF STRUGGLE, A TIME OF PERSEVERANCE

香港中學文憑考試(HKDSE)是一個人生很重要的里程碑。坊間常言道：「一試定生死」，這個準備多年的考試，背後的影響可能是一輩子的道路。然而，成績如何又是否真的代表了一切呢？今年的公開試發生在疫症蔓延時，心童桐桐亦是其中一名應屆考生，面對疫情所帶來的不安，她和媽媽都感到倍添壓力。

桐桐自小患有動脈導管未閉(PDA)，並於一歲時進行了手術，目前只需要定期覆診。由於情況穩定，中學的校園生活對於桐桐來說並沒有太大影響。基於疫情的關係，桐桐高中的三年大部份時候都是以網上課程中度過，直到今年一月，本港疫情大爆發，在備考期不幸遇上疫情，考試安排亦可以說是前所未有的，甚至傳聞公開考試可能要取消。「當時確診數字一直高企，消息亦不斷變化，我們都一度憂慮女兒到最後會錯過應考機會，擔心她又要重新來過，再經歷多一年壓力。」桐桐媽媽憶述。當時，家人都十分擔心若果桐桐不幸染疫，身體的不適會為考試帶來影響，為了減低感染的風險，所以家人都會避免外出。

「學校原定安排了學生可以回校溫習，但最後因為疫情他們都只能留在家中。缺少了支援，學生都感到十分無助，產生了孤軍作戰的感覺。」桐桐說。基於各方面所帶來的壓力，桐桐身體開始發出警號，出現了胸悶的情況。「作為心童家長聽到當然緊張，擔心會否是身體出了問題，於是立即鼓勵她溫習以外都要做一些放鬆運動，保持心境平靜，幸好症狀很快就消除了。」桐桐媽媽說。

經歷了這個難忘的考試，桐桐與媽媽都有深刻的感受。媽媽認為其實作為心童家長，沒有任何東西比子女的健康快樂更重要，只要她有努力過，不管最後成績如何都十分感恩。而桐桐則十分感謝家人的支持，協助她舒緩情緒，並寄語其他心童：「只要堅持不懈，就可以走出屬於自己的路！」

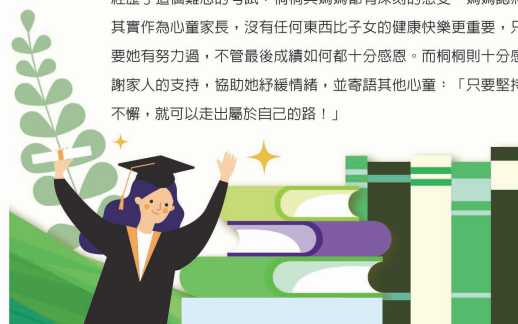


"Hong Kong Diploma of Secondary Education Examination (DSE) is a matter of life and future", having the public examination is a very important milestone in our life. However, are the results really everything? This year's public exams took place at a time when the COVID-19 was spreading, our member Hei Tung was one of the examination candidate, she and her parents felt stressed by facing the uncertainty of the exams.

Hei Tung suffer from Patent Ductus Arteriosus (PDA) since she was born and had surgery at the age of one. As her condition is stable, her school life in secondary school has not been affected much. Due to the COVID-19, Hei Tung spent most of her three years of high school on online courses. Start from 2022, the epidemic broke out in Hong Kong and unfortunately the exams needed to be postponed, or maybe cancelled. "The number of confirmed cases was high and the arrangement of the exam was kept changing. We are afraid that she will miss the chance of having the exam, and need to repeat for another year." Hei Tung's mother said. At that time, the family had been very anxious about if Hei Tung was infected. Her physical discomfort would have affected her performance in the exams. Therefore, they avoided going out in order to reduce the risk of infection.

"The school had originally arranged for them to go back to school for revision. But, at the end we had to stay at home due to the epidemic. I felt helpless and alone." Hei Tung said. Due to the stress from all sides, Hei Tung's body started to sound an alarm and she felt little chest tightness. "As a parent of a child with congenital heart disease, I worried that it might be a physical problem, so I immediately encouraged her to do some relaxation exercises to keep her mind calm. Fortunately, the symptoms soon cleared up," said Hei Tung's mother.

After this unforgettable exam period, both Hei Tung and her mother have deep feelings. For Hei Tung's mother, as a parent of a child with congenital heart disease, nothings more important than the health and happiness of her child. Hei Tung thanked her family for their support, which helped her ease her emotions. She also would like to encourage other child with congenital heart disease: "If you persevere, you can make your own way!"





# 成長的代價

## THE PRICE OF GROWING UP

現年十一歲的逸熙出生時並不知道確診先天性心臟病，出院後到母嬰健康院檢查，醫生聽到逸熙的心臟有雜音，指示他需要即時再次入院，及後經過再三檢查，終於確診患有室中膈缺損（VSD）。

「當時再返回醫院，見到逸熙在氧氣箱內插滿喉管，那刻真的好難受，很多天情緒都非常不穩定，終日以淚洗臉。」當時逸熙媽媽的心情可說是晴天霹靂。及後醫生說逸熙情況穩定可以出院，日後則需要一定定期回醫院覆診，觀察者缺損位置的大小。

在逸熙的成長過程中，由於都還在觀察期，心臟的問題都沒有影響他的日常和校園生活。然而，逸熙於2歲時確診有自閉症譜系，一直到3歲才學會說句子，因此在社交能力上較同齡小朋友弱。一直到逸熙8歲，一個人生的重要關口出現了。由於他心臟缺損的位置未有隨著成長收細，所以醫生決定安排逸熙做手術。手術後兩個月逸熙便能正常回校上學，雖然手術對學業沒有太大影響，但社交及校園生活就有所改變。

「學校老師會安排逸熙每日小息時到校務處休息，因擔心他會在班房內被同學碰撞到。放學時學校會安排我到校務處接他放學，老師亦會親自陪同逸熙乘搭升降機。亦因擔心他會在校外參觀時出現突發狀況而沒法讓他參與，因此在他的康復期間，他與同學之間的互動難免減少了。」

「其實我都會當逸熙是一個正常健康的小朋友來照顧，不會特別遷就他，因為不希望他會把自己當成病人。」逸熙媽媽表示即使逸熙手術後情況已十分穩定，但他仍會覺得傷口一直都在，產生不少心理陰影。作為心童家長都有一定的壓力，「幸好我們得到兒童心臟基金會的幫忙，介紹了果果媽媽給我認識，她好主動講解給我知悉手術後照顧小朋友需要注意的事項。加上我原本認識的心童家長——欣欣媽媽，減少我對逸熙手術的擔憂。我和逸熙亦參與了基金會的藝術治療及心理輔導計劃，讓我倆從中減輕不少壓力。」

對於逸熙未來的期望，由於疫情期間剛碰上逸熙的中學呈分考試，逸熙媽媽希望他可以克服困難，順利入讀一間適合他的中學，並且能認識到真正的好朋友，健康快樂地成長。



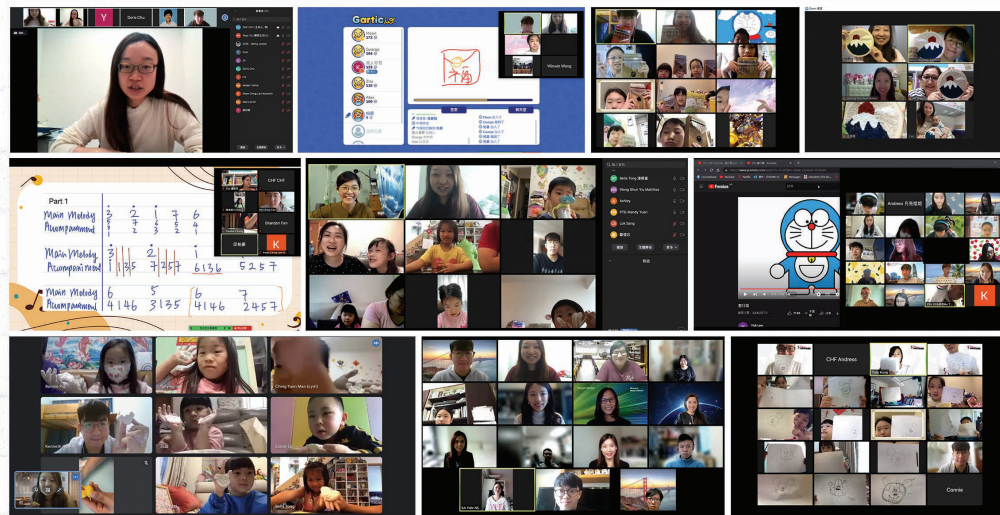
When Heison was born, he had not been diagnosed with any congenital heart diseases until they visited the Maternal and Child Health Centre. Upon his visit, the doctor heard a heart murmur and Heison was admitted immediately to the hospital again. After a few medical examinations, the doctors diagnosed him with Ventricular Septal Defect (VSD).

"When I came back to the hospital, I saw my son was put in the incubator with a tube in his throat. I was in tears for many days," said Heison's mother. The doctors explained that Heison's condition was stable enough to be discharged, but that he needs to return to the hospital regularly to keep track of the size of the septal defect.

Throughout Heison's growth, his heart problems did not affect his daily life or school life as he was still under observation. However, he was diagnosed with autistic spectrum disorder at the age of 2 and did not learn to speak in sentences until the age of 3, and therefore was relatively less sociable with other children of his age. Until Heison was 8, a critical juncture in his life occurred. The size of his septal defect has been enlarging as he grows up. Hence the doctors decided to arrange a surgery to repair the defect. Two months after the surgery, Heison was able to return to school. Although the operation did not affect his studies too much, his social and school life changed drastically. The teacher arranged Heison to take rest in the school office during break because they may be anxious about his classmates would have bumped on him in the classroom accidentally. His mother picks him up at the school office after school and the teacher takes the lift with Heison together, he could not participate in those school field trips. His teachers were concerned about any uncertainties may happen to him. As a result of this, his interactions with his fellow classmates inevitably decreased during his rehabilitation.

Heison's mother said that "in reality, I always treat and take care of Heison as a normal, healthy child, and will not give him any special treat because I do not want him to think of himself as a patient." Heison's mother says that he still feels as if the wound is still there although his condition is stable after the surgery, in which it creates a lot of post-traumatic stress. As a parent of a child with heart condition, there might be certain amount of stress to be suffered. Heison's mother remarked that "Fortunately, the Children's Heart Foundation offer us a helping hand. There are many parents sharing their advices on taking care of post-operation child. In the meantime, Heison was able to participate in the art therapy programme and I also received psychological support, which helped us both relieve a lot of pressure."

Heison's assessments for secondary school places allocation amid the epidemic, his mother hopes that he can overcome his difficulties and be admitted to a suitable secondary school.



### ◆ 疫流之旅

早前第五波的疫情嚴峻，相信心童家庭的生活都大受影響，不單只取消了實體課，更突然宣布提早放暑假，很多家長都措手不及。基金會深明家長的心情，亦十分關注心童的身心發展及情緒健康，所以用最快速的時間，籌辦了一系列網上活動，當中涵蓋各類型的範疇。

### ◆ 興趣班/技能訓練

- 香港迪士尼義工隊 X 基金會：Disney繪遊班
- 摩根士丹利 X 基金會：我終於變大個！面試技巧訓練班
- 手指琴班（入門班及進階班）
- 俄羅斯刺繡體驗班
- 唱遊樂趣多

### ◆ 遊出我心途活動

- 小小藝術家
- 家長都要喇喇氣
- 親子遊戲治療工作坊
- 音樂連繫我們：親子音樂互動及小樂器創作小組

### ◆ 休閒玩樂

- 幼兒樂趣多
- Board Game之鬼
- 密室逃脫小組
- 每日一遊 網上小遊戲挑戰

### ◆ Journey Under The Epidemic

During the fifth wave of COVID-19 epidemic, the lives of the families of children with congenital heart defects were greatly affected. Many parents were caught off guard by the cancellation of classes at school and the sudden announcement of an early summer vacation. CHF is concerned about the physical, mental and emotional well-being of our children. We have organised a series of online activities within the shortest time.

### ◆ Interest Classes/ Skills Training

- Disneyland Volunteer Team X CHF: Disney Drawing Class
- Morgan Stanley X CHF: Interview Skills Training Class
- Kalimba Class (Beginner & Advanced)
- Punch Needle Embroidery Class
- Fun Singing Class

### ◆ Journey Into Your Heart Activities

- Little Creator
- Parent's counselling group
- Parent-Child Play Therapy Seminar
- Linking with Music: Parent-Child Music Interaction & Instrument Creation Group

### ◆ Leisure and Fun Game

- Fun group for kids
- Board Game Playing Group
- Escape Room Playing Group
- Online Challenges For Everyday



# 遊出我心途 走進孩子的世界：親子遊戲輔導技巧

JOURNEY INTO YOUR HEART

| 文章 王健屏姑娘 (註冊遊戲治療師) MISS IVY WONG (REGISTERED PLAY THERAPIST)



親子遊戲治療是兒童為本(CHILD-CENTRED PLAY THERAPY)其中的一支派，故其核心價值是以「兒童為本」的心理理念而出發：提醒成人或家長，需要「聆聽」、「明白」及「接納」每個兒童的特性。兒童的父母親或照顧者被訓練來跟兒童一起進行遊戲治療，相比治療師，父母親對兒童的生活更具重要性，兒童亦會更容易接受。

Journey Into Your Heart — Stepping into children's world: Skills of parent-child play therapy. Parent-child play therapy is an element of child-centered play therapy, hence its core values are based around the core concept of "child-centeredness": the need to listen, understand, and accept each child's characteristic. Compared to a therapist, a child's parents or guardians are more important and the child is more receptive towards them, during a play therapy session.

Parents can set up a "special playtime" with their children - through a minimum of 30 minutes of playtime at a specific time and place each week. The game should be driven by the child and parents can adopt the three principles of "no questioning, no teaching, no praising" to allow children to express their thoughts and emotions freely.

Parents can also use the following parent-child play therapy techniques:

### 1. Describe the child's behaviour and motivation

Parents can describe the child's actions, e.g. "You are playing with this ..." without naming the toy. This indirectly conveys the message of your presence for the child, allowing them to feel cared for, understood and accepted, thus making it easier for the child to share their thoughts with their parents.

### 2. Acknowledge and responds to the child's feelings

Parents can try to put themselves in the child's shoes by using different emotional words to guess or speak on their behalf and help the child understand their behaviour.

### 3. Encouragement

Instead of praising results or performance, parents can try to encourage their children. For example, instead of offering help immediately when a child fails to complete a task, parents can allow the child to continue trying and use words of encouragement to acknowledge the child's effort. In doing so, this will help the child in developing their sense of self-esteem and competence and reduce dependency on the parent.

### 4. Therapeutic limitations

When a child is engaging in a dangerous act or being uncooperative, parents should first acknowledge the child's feelings and let the child know that the parent understands how they are feeling, and from thereon state the limitations of the session and propose alternatives. For example, when a child is agitated and wants to hit someone, the parents need to acknowledge the child's feeling of anger but also emphasize that hitting is not allowed. From there, the parent may suggest that the child can hit a doll to vent their feelings.

Although parents are unable to always relate to their children's thoughts, but with time and patience and the aforementioned techniques, they can gradually enter their children's world and become their most important listeners and companions.

家長可以與孩子訂立「特別遊戲時間」— 透過每星期於特定時間，特定地點，進行不少於30分鐘的遊戲時間。遊戲過程以孩子作主導，家長可採取「不發問、不教導、不讚賞」的三大原則，讓小朋友自由表達想法及情緒。

家長亦可以運用以下的親子遊戲輔導技巧：

### 1. 描述行為及動機

家長可以透過形容孩子的行為，例如：「你在玩這個……」，過程中無需為玩具命名，另外可以間接向孩子表達「我在這裡」或「我在聆聽」的訊息，讓他們感到被關注、明白及接納，從而令孩子更容易向家長分享內心想法。

### 2. 確認和回應孩子的感受

家長可以嘗試代入孩子的想法，利用不同情緒詞彙，猜出或代他們說出心聲，幫助小朋友認識自己的感覺，例如當孩子說：「壞人快過到來」，家長可以說：「真的喔，好緊張呀！」。

### 3. 鼓勵

家長可以嘗試鼓勵孩子，而非讚賞結果或表現。例如當孩子沒法完成時，家長不應立即主動幫忙，而是容許孩子繼續嘗試，並運用鼓勵說話去肯定孩子的努力。這可以協助孩子建立自尊感及能力感，減少依賴家長。

### 4. 治療性設限

當孩子出現傷害性行為或不合作時，家長應先確認孩子的感受，讓孩子知道家長是理解他們的心情，繼而向孩子陳述所定立的限制，並提出取代方案。例如當孩子激動得想打人，家長需要表示了解孩子的憤怒感覺，但要強調打人不容許的，接著提出孩子可以透過打公仔以發洩當中感受。

儘管家長未必能夠百分百代入孩子的想法，然而只要多付出時間和耐性，並透過以上的技巧，便能慢慢走進孩子的世界，成為孩子最重要的聆聽和陪伴者。

### 不發問

除了在進行角色扮演遊戲外，家長都不去問孩子問題，讓小朋友帶領整個特別遊戲時間。

### 不教導

家長不教導孩子應該怎樣做，怎樣玩，讓小孩盡情發揮創意。

### 不讚賞

遊戲中讚賞孩子可能會令孩子為得到讚賞，而表現得刻意符合家長期望，從而失去自主性。

### No questions asked

Except during roleplay, parents should not ask the child any questions, allowing the child to lead the entire special playtime.

### Non-teaching

Parents should not teach their children what to do, how to play, allowing them to be as creative as they want to be.

### No praise

Praising children during play can lead to children acting out to meet parental expectations in order to receive praise, thus losing their autonomy.

# 先天性心臟病兒童 需要言語治療嗎？

DO CHILDREN WITH CONGENITAL HEART DISEASE NEED SPEECH THERAPY?

| 文章 姚鶯欣 (言語治療師) YOYO YIU (SPEECH THERAPIST)



言語治療的服務範圍不限於發音，而是涵蓋語言、吞嚥、進食、聲線及聽障康復等領域。在這些方面有困難的兒童需要接受言語治療師的服務，當中包括患有先天性心臟病的兒童（心童）。

Service scope of speech therapy does not limit to speech production, but covers a wide range of areas such as language, feeding and swallowing, voice, auditory rehabilitation, etc. Children having difficulties in these areas may need to see a speech therapist. A child with congenital heart disease could be one of them.

先天性心臟病有可能令兒童心肺不穩和腸道灌注不足，導致餵食困難。他們會在餵食時出汗、迅速疲勞或經常嘔吐。治療過程如頻繁禁食和餵飼高營養奶有機會進一步引致病童對食物缺乏興趣、「揀飲擇食」，甚至抗拒進食，有礙兒童的發育和成長。言語治療師會按病情情況建議個人化的餵食技巧，包括給予休息、少食多餐和姿勢調整以控制症狀，而這些問題大多隨著心臟狀況改善逐漸減少。

Due to the heart condition, children may suffer from cardiac-respiratory instability and hypoperfused intestine which may cause feeding difficulties. They may sweat during feeding, fatigue quickly or vomit more than often. Medical procedure or treatment including frequent fasting and high-concentration energy feeds may further affect children's interest in food, and lead to food selectivity or even oral aversion. As a result, children would have poor weight gain and growth. Speech therapists would advise on individualized techniques including adopting breaks, small-frequent feeds, and posture modification for symptoms control, while these problems may gradually subside when heart condition improves.

病童亦有可能出現吞嚥困難，在進食時不能在吸吮、吞嚥和呼吸之間協調好，吞嚥與呼吸同時發生，導致食物進入氣管。此外，神經系統受損、患有其他綜合症、或因心臟手術而損害喉嚨神經線的兒童有更高的吸入風險。若在臨床評估中發現吞嚥風險，言語治療師會安排儀器檢查，如內窺鏡吞嚥檢查和X光造影檢查以了解吞嚥困難的成因，建議補償方法(如改變食物的濃稠度、份量、流速或姿勢)並提供治療，以達致安全進食。

Dysphagia (swallowing difficulty) is found in some children who could not coordinate well among suck, swallow, and breathe during feeding. Their swallow occurs at the same time as a breath, resulting in food going into the airway (i.e., aspiration). Furthermore, children are more prone to aspiration if they have neurological sequelae or other comorbid syndromes, or have undergone cardiac surgery which the nerve that controls the larynx is prone to injury. Speech therapists would arrange instrumental assessment like Flexible Endoscopic Evaluation of Swallowing and Videofluoroscopic Swallow Study, subsequent to identification of aspiration risks in clinical swallow evaluation. With better understanding on pathophysiology of dysphagia, speech therapists would make recommendation on compensation (such as bolus control by consistency, size and flow rate, as well as posture) and provide treatment to reduce, or even eliminate, the risk.

除了餵食問題，許多父母關心孩子的言語和語言發展。文獻顯示，除非病童同時患有其他影響言語和語言發展的疾病（如唐氏綜合症或其他發展障礙），否則心童雖然在兩歲前會表達的詞彙可能較少，但整體溝通能力亦算良好。至於語言方面，沒有證據顯示心臟病會導致病童發音不準確，然而所有兒童在六歲之前都有可能出現發展性發音錯誤，他們將會通過回饋和對口部肌肉逐步成熟的控制，包括嘴唇、舌頭和腭，而逐漸準確地咬字。

Apart from feeding issues, many parents are concerned with their children's speech and language development. Unless there are comorbidities such as Down syndrome or other developmental disorders which may affect speech and language acquisition, evidence suggested children with congenital heart diseases are able to communicate without much problem despite limited expressive vocabularies at younger age. As for speech production, there is no evidence suggesting correlation between articulation problems and paediatric heart disease. All children including typically developing ones may have developmental articulation errors before 6 years old, that they would acquire the sounds gradually with feedback and better control of articulators including their lip, tongue and jaw.

如果您的孩子出現以上的問題，就有需要言語治療服務。除了言語治療師的介入外，父母和家人的意見，以及緊密的醫患合作，對治療結果以及患有病童的整體發展都具有重要意義。



Speech therapy is indicated if your child is having these common problems found in patients with paediatric heart disease. Along with the input by speech therapists, a close collaboration based on parents and family's feedback is significant to the treatment outcomes as well as the development of children with congenital heart disease.



## 從懷孕到誕生 打勝仗的小勇士

THE WARRIOR FIGHTS AGAINST CONGENITAL HEART DISEASE

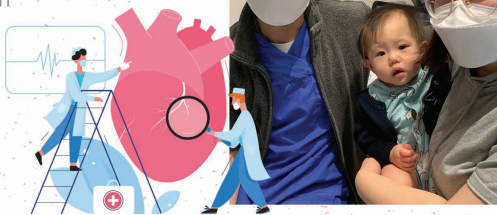
文章 陳妍嘉家長 AUTHOR CIRCLE CHAN'S PARENT

今年二零二二年，六月二十一日，陳妍嘉迎來一歲生日了！

二零二一年三月五日，我懷著妍嘉，第一次與先生懷著沉重的心情，第一次踏足兒童醫院，第一次見到羅冠中醫生和周百昌醫生——妍嘉的兩個救命恩人。當時周百昌醫生診斷出妍嘉是典型的大血管異位（簡稱：TGA），就是兩條心臟主要大血管錯位，出世若不加以治療，將兩條血管矯正位置，心臟便不能輸送帶氧血到身體各個器官，就會引致缺氧甚至死亡。聽到消息後，我和先生反而是鬆一口氣，因為這令我們再次有了希望。猶記得，聽完兩位醫生專業的見解，走的一刻，我四個都是笑著的。

一切都緣於我私家婦產科鄭昆瑜醫生的細心，令我產前16週已知道妍嘉有TGA，隨即拿了轉介信到伊利沙伯醫院抽羊水及作進一步檢查。那一刻心情好像一大團雲包圍著我，及後醫生懷疑她不止有TGA，還有右心室雙出口，她對我說手術成功率由95%跌到50%，剎那間屋漏偏逢連夜雨。當時，心情好迷茫，因為網上資訊不多，也找不到同路人，無人可以話我知。「還有前路嗎？」、「我將要面對些什麼？」幸運地，我找到兒童心臟基金會，社工張姑娘好快就幫我找到兩個心童家長，和我分享他們走過的路，教我主動向醫生發問。最後，我終於爭取到在22週6天見兒童醫院的羅冠中醫生和周百昌醫生。

特別感謝周百昌醫生，每次產前心臟超聲波，周醫生都用一百分的認真，專注去診斷妍嘉那小小的心，比核桃更細的心臟。最長一次他望住螢幕中的心臟，用了一小時十五分鐘。媽媽我曾經都想一齊望，但我試過望了十分鐘，那強而有力的心臟膜不停蠕動，已令我覺得頭暈。雖然好多人認為做手術，外科醫生算是最重要，但我認為內科醫生術前術後的陪伴、情緒上的支援、同理心，才是致勝的關鍵。周醫生每次都會主動解答我心中的疑問，儘管我每次不停重覆問題，但他依然不厭其煩地用專業的知識、多年的經驗、肯定的語氣，安撫我心中的不安，令我們一家人有勇氣去陪妍嘉面對她將要遇到的挑戰。



Circle, my daughter, celebrates her first birthday on June 21, 2022!

On March 5, 2021, Circle was still in my womb. This was the first time for my husband and I entered into Hong Kong Children's Hospital. We went there with heavy heart and aimed to seeking help from Dr Barnabe Antonio Rocha and Dr Chow Pak Cheong, the saviours of my daughter's life. Dr Chow told us that Circle was suffering from Transposition of the Great Arteries (TGA), in which the two major blood vessels of the heart were misaligned. If it was left untreated, the two blood vessels would be reversed and the heart would not be able to carry oxygenated blood to the rest of the body, possibly lead to death. This message means we still have hope. My husband and I felt relieved. I can still remember that after listening to the professional advices, all four of us were smiling as we stepped out the hospital.

Dr Cheng Kwun Yue's attentive care during my private obstetrics and gynecology visits made me realise earlier that Circle was suffering from TGA, 16 weeks before delivery. I brought the referral letter to Queen Elizabeth Hospital immediately for amniocentesis and further tests. At that moment, I felt a dark cloud had surrounded me. Later, the doctor also suspected that not only did she have TGA, but also double right ventricular outlet. Dr Cheng explained that this condition would reduce the chances of success of the surgery from 95% to 50%. I was very lost at that moment, as there was not much information on the Internet. In the meantime, I could not find anyone who could tell me what to do. Fortunately, I found the Children's Heart Foundation. Ms. Cheung, the social worker, introduced me two parents of children suffering from congenital heart diseases. They share with me their experiences about taking care of congenital heart defects children and recommend me to take the initiative to consult the doctors. Finally, on the 22 weeks and 6 days, I was able to meet with Dr Barnabe Antonio Rocha and Dr Chow Pak Cheong at the Children's Hospital.

I would like to take this opportunity to thank Dr Chow for his dedication and attentiveness to make proper diagnosis of the tiny heart of Circle during every antenatal echocardiogram examination. I couldn't believe that he spent one hour and fifteen minutes in observing the movement of the valves of the heart on the screen. As I intended to take a look on the screen as Dr Chow did, I felt dizzy after ten minutes. Although many people may think that the surgeon is the most important person in a surgery, I am sure that the medical personnel provide pre- and post-operation support, emotional support and empathy are of utmost importance for the success. I appreciated that Dr Chow always took the initiative to answer my questions and even I kept repeating questions, he always reassured me with his professional knowledge, experiences and affirmative tone.

在妍嘉出世後的第七日，感謝羅冠中醫生執刀，七小時的大血管轉位手術順利完成。雖然術後心臟有少許腫及跳得慢，中途亦出現併發症氣胸，但全靠一眾兒科心臟科醫生、兒童深切治療部的醫生及護士們的努力，妍嘉很快由兒童深切治療部轉去3S心臟病房。即使心臟病房人手短缺，他們真的很忙很忙，但所有的醫生、護士、甚至病房助理都很有愛心，照顧了妍嘉前後接近兩個月的時間。

手術後的小插曲，就是妍嘉對手術用的其中一條鋼線出現排斥。當時，她的傷口經歷發炎、縫針、清創手術，但傷口在出院十三日後，再次會膿裂開，我又回到了3S心臟病房。再次感謝羅冠中醫生，為妍嘉找出傷口反覆會膿的原因，認為她對某條手術鋼線排斥。及後覆診時醫生曾說排斥機會率十分之低，可說是運氣不好，不過當時做了拆走鋼線小手術後，幸運地可趕及在兩個月大時回家慶祝。

出院後，由於TGA的嬰兒很容易有肺動脈狹窄的問題，少不免要再次回到兒童醫院，進行大大小小的檢查和覆診，但不同的是，我們的心充滿著幸福。早前在十個月大的心臟超聲波中，妍嘉的肺動脈因為位置上的問題，很難清楚照到，照了大半個鐘都照不到。第二次再照時，小確幸地撞見周百昌醫生經過，已經八個月無見過，見到他可說是興奮過見到偶像！我聽護士說他原本主力為產前的孕婦照聲波，但他超級好，主動幫妍嘉照那條很難照到的肺動脈，亦將我們的一絲擔憂掃走，最後還合照成功。

希望妍嘉長大後，學懂心存感恩，知道陪伴她走過危險低谷的周醫生模樣，就像詩篇所說：「我雖然行過死蔭的山谷，也不怕遭受傷害，因為你與我同在；你的杖和你的竿都安慰我。」

我明白到醫生不是神，只要是手術就有風險，無可能百分之百成功，更何況是人體最重要的心臟？然而，前路就只有兩條，既然其中一條有機會成功，作為父母都想嘗試，不管結果如何，但求無愧於心。我覺得心童選中我們做她的父母，就是相信我們有能力去承擔和面對。我感恩這兩個月的經歷，令我一家人更相愛，更珍惜彼此。同時，要多謝我的丈夫，在我坐月子期間不讓我操勞，日日風雨不改，收工就去探望妍嘉，視像讓我可以望望女兒。



羅醫生同周醫生不但救了妍嘉，亦拯救了我們一家四口，感恩之心，永在心頭。希望能夠有更多年輕醫生加入兒童心臟科，拯救心童們，以生命影響生命。另外，祝福所有心童都能健康快樂成長，做一個打勝仗的勇士。

On Circle's seventh day from birth,

the seven-hour major vascular reversal operation was completed successfully. We thank Dr Barnabe Antonio Rocha for everything he did. Although my daughter's heart was slightly swollen and slow heart beat after the surgery together with complications of pneumothorax in the middle of the operation, with all the might of the paediatric cardiologists, doctors and nurses from the Paediatric Intensive Care Unit, my daughter was able to be transferred from the ICU to the 3S cardiac ward in no time. Even though the manpower of the cardiac ward was tight and busy, all the doctors and nurses and healthcare workers have been working hard and taking care of this little infant for almost two months.

A minor post-operative incident was the rejection of one of the steel wires used in the surgery. At the time, her wound had been inflamed, stitched up and cleaned up, but 13 days after being discharged from the hospital, the wound opened up with pus again and we were back in the cardiac ward. Once again, I would like to thank Dr Barnabe Antonio Rocha for identifying the cause of the pus in her wound. After identifying the cause, we were able to get back home in time to celebrate my daughter's two months celebration.

The infants with TGA are easily prone to pulmonary artery stenosis. It was inevitable that we had to go back to the Children's Hospital for all sorts of tests and follow-up treatments. At Circle's 10 months of age, it was difficult to get a clear echocardiogram image of her pulmonary artery. In her second echocardiogram, we were lucky to have Dr Chow's good hand again. He helped us identify the pulmonary artery on the echocardiogram, which relieved our worries.

I hope that Circle will learn to be thankful and remember Dr. Chow has helped her going through difficulties. Psalms : 'Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me.'

I understand that doctors aren't god. There are risks hidden in every surgery. Yet, there are only two ways to go. No matter which one would have a chance of success, we want to give it a try. No matter what the outcome would be, just do it without regret. I think the reason of the children with congenital heart diseases choose us as their parents because they trust our strength to take on the challenge. I am thankful for the experience I gained in these two months. It has made my family love and cherish each other more. At the same time, I would like to thank my husband for reminding me not to put too much pressure on myself during my post-partum recovery and video-calling me so that I could see my daughter while I stayed at home.

Dr Barnabe Antonio Rocha and Dr Chow not only saved Circle's life, but also saving our family of four. We are eternally thankful for their immeasurable help. I hope that more and more young upcoming doctors will consider joining the paediatric cardiology department to save more children. In addition, I wish all the children with congenital heart disease will grow up healthily and happily.



## 我最喜愛的電影/劇集

MY FAVOURITE MOVIE/DRAMA

| 文章 曾建成 AUTHOR TSANG KIN SHING

今天我想和大家分享的是我在疫情期間觀看的一部電視劇—《星空下的仁醫》。這一套電視劇故事講述很多患有長期病患的兒童病人，他們大半時間都在醫院裏渡過。由於我以往亦是大部分時間都在不斷出入醫院，因此我每次看這套電視劇，都像帶我進入到當時的情景，感受到患有長期病患兒童的痛！當中特別是有一集講述一個患有先天性心臟病的初生嬰兒，令我十分感同身受，我明白到原來當父母知道他們自己的子女患有先天性心臟病時所感到的驚恐及自責。

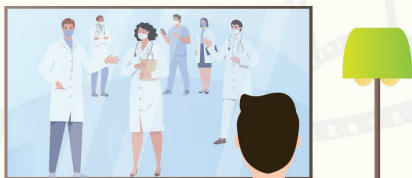
我想推介這套電視劇的原因是希望令更多人知道患有長期病患的兒童的處境，我們都會努力生存下去及堅持打好每一場仗。讓他人知道心童雖然是長期病患者，但其實我們亦可以選擇適合的活動跟其他人一起玩樂。

最後，希望所有和我一樣患有先天性心臟病的朋友們，都可以像電視劇裏的兒童一樣，堅持下去並活出一個不一樣的人生，珍惜大家得來不易的生命。

Today I would like to share with you a TV drama I watched during the COVID-19 epidemic - 'Kids' Lives Matter'. It is about the children with chronic illnesses who spend most of their time in hospitals. As I used to spend most of my time in and out of the hospitals when I was a little boy, this TV drama reminded me the experience of living in the hospital and felt the pain of those children as every time I watched it. In particular, there was one episode about a new-born baby with congenital heart disease that projected the parents' horror and remorse when they found out that their child had a congenital heart disease.

The reason I wanted to introduce this TV drama was to make more people aware of the situation of the children with chronic illnesses. The way that the kids tried to survive and fought every battle as well as to let others know that the children with chronic illnesses still can play with others like normal children.

Finally, I hope that all of you who suffer from congenital heart disease like me can persevere and live a different life, just like the children in the TV drama, and cherish the life you have.



| 文章 吳冬妮 AUTHOR NG TUNG NI

我想和大家分享我在疫情期間觀看的一部電影—《阿甘正傳》，這一套電影是一部比較舊的電影，如果經常看電影的人應該對它也不陌生。當我一開始看的時候其實我覺得挺無聊，但是看了一段時間之後就覺得感同身受，因為故事中的主角儘管智力不足且行動不便，仍盡自己所能去做好每一件事情，替他帶來許多美好的結果，活出精彩無比的人生。

我想推介的原因是因為整套電影令我感同身受，因為我患有先天性心臟病，患上這個病會比一般人有更多的限制，例如在運動方面，當我得到醫生的同意可以參加體育活動之後，我就被老師推薦參與學校的體育校隊，但是我因為疾病的原因，我和隊員之間的體力有很大的差別，經常被教練「特別關注」。然而，當時我也沒有放棄，繼續努力訓練，有時候練到體力透支，就是為跟上隊員的腳步，最後我也與隊員一起去參加比賽且順利贏得勝利。雖然今天我因為學業的原因退出了體育校隊，但是至今我也沒有感到後悔，就像電影中的主角一樣盡自己所能去做好每一件事情，帶來許多美好的結果。

「人生有如一盒巧克力，你永远不知道你會拿到哪一顆！」所以在這裡，我希望患上先天性心臟病的朋友，可以像電影中的主角一樣，積極面對人生，好好的活在當下！

I would like to share with you a film that I watched during the COVID-19 which called "Forrest Gump". When I first watched it, I found it quite boring. But after watched it for a while, I could relate to the situation of the leading role in the story. Despite of his lack of intelligence and limited mobility, he still worked hard on everything he could and led to many good results and lived a wonderful life.

The reason I want to recommend it is that my experience can relate to the whole film. I was born with a congenital heart disease, which imposes more limitations than the average person, especially on sports. After the doctor said I can play sports, I was invited to join the school team by the teachers. Due to this illness, I am different from others on physical strength, therefore, the coach was often "attentive" to me. However, I didn't give up and continued to work harder on training. I just wanted to keep up with my teammates, and eventually I went to competitions with them and won the game. Even though I quit the sports team today for my studies, I won't regret. Just like the leading role in the movie, I did everything I could to bring about many good results.

"Life is like a box of chocolates, you never know which one you're going to get." So here's hoping that people with congenital heart disease can face life positively and live in the moment.

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 地址 Address: \_\_\_\_\_  
 電話 Tel: \_\_\_\_\_ 電郵 Email: \_\_\_\_\_

需要發出捐款收據 (適用於捐款 HK\$100 或以上) Donation receipt is required (For donations of HK\$100 or above.)  
 若收據抬頭與捐款者不同，請註明 Please state if receipt title is different with donor:

### 捐款方法 Donation Method

- PAYME  
 請開啓PAYME手機應用程式，掃描以下二維碼進行捐款，並於訊息欄輸入參考資料 (例子: Donation, Chan Tai Man, Tel: 25530331)，以供識別。  
 Please scan the below QR Code through your mobile PAYME app.  
 Input a message remarks (e.g: Donation, Chan Tai Man, Tel: 2553 - 0331). 
- 以劃線支票捐款，抬頭請寫「兒童心臟基金會」。By a crossed cheque made payable to "Children's Heart Foundation".  
 支票號碼 Cheque No.: \_\_\_\_\_
- 直接存款 / 透過銀通或自動櫃員機轉帳至渣打銀行 (香港) 有限公司「兒童心臟基金會」之銀行戶口。  
 Direct deposit / through "Jetco" or "ATM" transfer to CHF bank account at Standard Chartered Bank (HK)  
 帳戶號碼 Account no.: **447-1-034943-5**
- 轉數快 Faster Payment System (FPS)  
 請開啓銀行機構的手機應用程式，輸入快速支付系統識別碼 (FPS ID) : **160893608**。  
 轉賬至: **CHILDREN'S HEART FOUNDATION**，並於訊息欄輸入參考資料 (例子: Donation, Chan Tai Man, Tel: 25530331)，以供識別。  
 Please insert FPS registered ID: **160893608** through your mobile banking app.  
 Transfer to: **CHILDREN'S HEART FOUNDATION**. Input a message remarks (e.g: Donation, Chan Tai Man, Tel: 2553 - 0331).
- 銀行戶口每月自動轉賬 Bank account monthly autopay  
 請下載銀行戶口轉賬授權書。 <http://www.childheart.org.hk/TR/Doc/DDAF.PDF>  
 Please download the Bank Direct Debit Authorization Form. 
- 到 7-Eleven 捐款 Make donation at 7-Eleven  
 只需攜同以下捐款二維碼到全港任何一間7-Eleven，以現金捐款便可 (每次捐款金額最少為港幣一百元)。  
 Present below donation QR Code to any 7-Eleven stores in HK when making a cash donation to CHF.  
 The minimum donation amount is HK\$100 per transaction. 
- 透過信用卡捐款 By Credit Card <http://www.childheart.org.hk/TR/odf.asp> 

請將表格連同每月自動轉賬表格 / 銀行入數紙 / 支票電郵、傳真或郵寄至兒童心臟基金會。  
 Please return this form together with monthly auto-pay authorization form / bank-in slip / cheque to the CHF by fax/email/post.

\* 兒童心臟基金會是根據《稅務條例》第88條獲豁免繳稅屬公共性質的慈善團體。捐款港幣一百元以上可獲發收據。  
 若閣下需要捐款收據，請同時附上您的姓名、地址及聯絡電話。  
 Children's Heart Foundation is a charitable institution of a public character exempt from tax under Section 88 of the Inland Revenue Ordinance. Receipts will be issued for donations of HK\$100 or above.  
 If you need an official receipt, please send the crossed cheque along with your name, address and contact telephone number.

\* 基金會將按上述資料與閣下保持聯絡，定期介紹基金會活動及發收據之用。一切資料，絕對保密。  
 Data collected will be treated strictly confidential and will be used for issuing receipt and sending information on CHF's activities only.

背面請印回郵地址。 Please find the return address at the back.