

# **Transition Care for Paediatric Patients with Chronic Illnesses to Adulthood**

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8 May 2018.



# Challenges with Chronic Illnesses

- Social adjustment
- Change in life styles
- Disease management



# Challenges during Transition:

- Differences between systems of paediatric & adult.
- Varied perspectives from patients, families & health professionals.
- Differences of respective developmental stages.



# Outcomes of Poor Transitional Process:

- Suboptimal health outcomes.
- Drop out from the health care system.



# The **definition** of Transitional Care for Adolescents

“ The purposeful, planned movement of adolescents and young adults with chronic illness/ disability from **child-centered** to **adult-oriented systems** ”

( Blum, 1993)



# The Goal of the Transitional Care

To maximize lifelong functioning and potential through the provision of high-quality developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood

( American Academy of Pediatrics etc., 2002).





# Transitional Care Program in United Christian Hospital

- Started since 2011
- For diabetes,  $\beta$  thalassemia major patients
- Extended to epilepsy patients in 2018



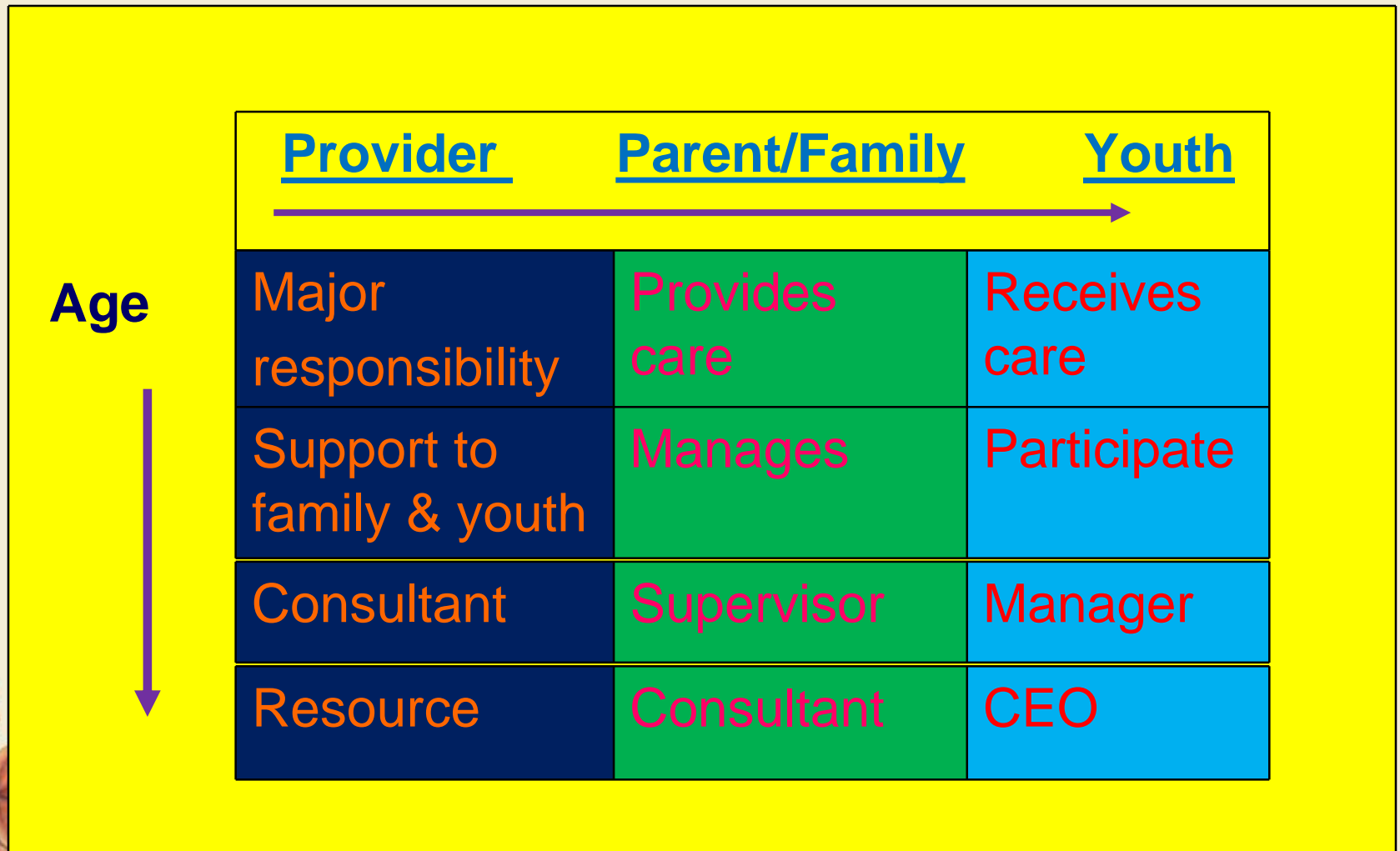
# The Target Group

- Age:  $\geq$  14 years old
- Higher priority for the age  $\geq$  18 years old
- Chronic illness : DM,  $\beta$  thalassemia, Epilepsy





**Transition Model:**  
**Shared Management Model**  
(Kieckhefer GM & Trahms CM, 2000)



# Program content

1. Ongoing assessment & counselling by various TOOLS in the transition care program.
2. Peer group support.
3. Post-transition phone follow up.



# 1. Ongoing assessment & counselling

- **Transition Assessment Booklet:**  
Evaluate individual skills in disease management & self-awareness of independence.
- **My Health Passport:**  
Help patient's understanding of disease.
- **Role play** to train up self-advocacy skills.



# Transition Assessment Booklet

## Hospital Authority

### Transition Assessment for Adolescents with Chronic Illness

This assessment tool assists health care providers managing adolescent requiring transition from paediatric to adult medical care. Adolescents should be prepared for transition early, generally from age 12 to 14. As adolescents have different development milestones and illness patterns, this general tool could be modified and adopted according to clinical judgment.

#### Content

1	Medical History.....	p.2
2	Readiness for Transition.....	p.3
2.1	Health Care Provider Transition Checklist and Timeline.....	p.3
2.1.1	Lead questions.....	p.4
2.2	Young Person Questionnaire.....	p.5
2.3	Parent/Caregiver Questionnaire.....	p.6
2.4	Assessing transition skills of adolescents with chronic illness.....	p.7
2.4.1	Lead questions.....	p.8
3	Adult health service.....	p.9
4	Support services.....	p.9
4.1	Social service.....	p.9
4.2	Education/vocational service.....	p.9
4.3	Patient support group.....	p.9
4.4	Others.....	p.10
5	Review of transition care.....	p.10
6	Enquires.....	p.10

# Assessment of Transition Skills

## 2.4. Assessing transition skills of adolescents (for doctors)

Grade 1 = start of transition.

Grade 4 = skill achieved.

Insert  to indicate the transition skill achieved on the assessment day.

An adolescent is expected to achieve transition skills from grade 1 to 4 with time.



	Knowledge				Communication				Medication											
	Cause of disease		Disease effect on puberty & fertility		Disease effect on health		For doctor	Communication with doctor	Appointments and attendance	Medication knowledge		Taking medication								
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4				
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Ref: Towns S, Sampson S, Dicker J. Transition Care Practice Guidelines. Division of Adolescent Medicine, The Children's Hospital at Westmead, Sydney, Australia 2004.

# Assessment of Transition Skills

From grade 1 to 4

- **Knowledge:**

1. Cause of disease
2. Effect on puberty & fertility
3. Effect on health

- **Communication:**

1. Attending consultation with/without parents/caregivers
2. Communication in consultation
3. Booking appointment and keeping attendance

- **Medication**

1. Knowledge of medication
2. Independence of taking medication





# Young Person Questionnaire: Patient's own assessment of readiness

## 2.2. Young Person Questionnaire (for adolescents)

(every 6-12 months)

### 青少年裝備為成年人的健康自我評估表

姓名：

填寫日期：

1. 我不能夠
2. 我在考慮中
3. 我不知道
4. 我很快便會做到
5. 我已經做到

請在方格內☐上你的選擇。

	1	2	3	4	5	評語
1. 我能夠向他人解說我的長期病況。						
2. 我明白自己的健康狀況對我將來的影響。						
3. 我能夠向他人提出我的需要。						
4. 我成年後將會繼續找那位我喜歡的家庭醫生看病。						
5. 我知道我成年後需要看那一類別的醫生。						
6. 我有權知道自已的健康資料。						
7. 如我家人未能對我的健康提供幫助時，我可以找其他人幫助我。						
8. 我能夠準備及服用藥物。						
9. 若有需要時，我能夠自我治理。						
10. 我有記錄自已的藥物及何時要去看醫生。						
11. 當我生病時，我知道往那裡看病。						
12. 我有計劃怎樣去照顧自己。						

Adapted from:

Good 2 Go Transition Program, The Hospital for Sick Children, Canada. <http://www.sickkids.ca/good2go/>

# Parent/Caregiver Questionnaire: Parent's assessment of patient's readiness

## 2.3. Parent/Caregiver Questionnaire (for parents)

(Every 6-12 months)

### 家長對青少年裝備為成年人之健康評估表

姓名：

填寫日期：

1. 極不同意
2. 不同意
3. 未能決定
4. 同意
5. 極同意

請在方格內☐上你的選擇

	1	2	3	4	5	評語
1. 我的孩子有參與其健康護理之討論。						
2. 我的孩子有獨自與健康護理人員交談。						
3. 我的孩子明白他/她的健康狀況會怎樣影響到青春期的成長。						
4. 除朋友外，我的孩子能夠找到其他人提供性知識的資料。						
5. 我的孩子知道怎樣去防止被虐待、染上性病或懷孕。						
6. 我的孩子有一群相信和善待他/她的朋友。						
7. 我的孩子有參與他/她喜愛的組織、團體、運動和活動。						
8. 我的孩子在學校或工作上有固定的目標。						
9. 我的孩子明白喝酒、藥物濫用和吸煙的危險性。						
10. 我的孩子知道他/她不能夠參與那些有危險的活動。						

Adapted from:

Good 2 Go Transition Program, The Hospital for Sick Children, Canada. <http://www.sickkids.ca/good2go/>

# My Health Passport: Templates of a variety of Chronic Illnesses

Passport for Health - Windows Internet Explorer  
https://www.sickkids.ca/myhealthpassport/

**SickKids** Good 2 Go Transition Program -- MyHealth Passport

**Home**

Welcome to MyHealth Passport, a project that gives you instant access to your medical information, including the names of your medications for your child.

Start by filling out the information below

**CREATE PASSPORT**

Passport

**New Passport**

MyHealth Passport was conceived and created by The Hospital for Sick Children. Special thanks is given to Crescan Internet Solutions for their assistance.

MyHealth Passport is a customized, wallet-size card that gives you instant access to your medical information, including the names of your medications for your child. It is useful if you are in an emergency room or are writing your first novel and want to know what you are taking.

Diabetes  
Dyslipidemia  
Education  
Epilepsy  
FASD  
Generic Passport  
Genetic Metabolic  
Geriatric  
GJ Tube  
Heart transplant  
Hemophilia  
HIV AIDS  
Hydrocephalus UNDER CONSTRUCTION  
Inflammatory Bowel Disease  
Interstitial Lung Disease  
Intestinal Rehab  
Kidney  
Kidney Transplant  
Liver transplant  
LTX TESTING  
Lung transplant  
Lupus  
Marrow Failure  
MEDICATION RECORD  
Mental Health  
Morphea  
Multi organ transplant  
Multiple Sclerosis  
Muscular Dystrophy  
Myasthenia Gravis

Generously supported by the John Deere Foundation of Canada

**JOHN DEERE FOUNDATION**

The Hospital for Sick Children is not responsible for the information that you put into this passport or any use you put it to.

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開始 | Passport for He... | Transition revisited | HKPS AAP Trans... | Lau Sau Lai Appli... | Microsoft PowerP... | 20:56



# My Health Passport

## (Go through with patient by Transition Nurse)

PATIENT'S LABEL  
Without I.D.

寫日期: \_\_\_\_\_

**我的健康護照 (糖尿病)**

出生日期 \_\_\_\_\_

診斷: 一型糖尿病 ( )  
診斷: 二型糖尿病 ( )

患糖尿病之診斷日期 \_\_\_\_\_

外科病歷: 有  沒有   
若有, 曾作之手術名稱 \_\_\_\_\_  
作該手術之日期 \_\_\_\_\_

內科病歷: 有  沒有   
疾病名稱 \_\_\_\_\_  
敏感病歷: 有  敏感之物品 \_\_\_\_\_ 沒有

住院記錄: (由較遠的日期開始填寫)

住院日期 _____	疾病名稱 _____	入住醫院名稱 _____
住院日期 _____	疾病名稱 _____	入住醫院名稱 _____
住院日期 _____	疾病名稱 _____	入住醫院名稱 _____
住院日期 _____	疾病名稱 _____	入住醫院名稱 _____

糖尿病病歷:

7.1 正使用的注射胰島素名稱、種類、次數

筆型胰島素:

Humalog  Actrapid HM  
 Humulin N  Lantus  其他 \_\_\_\_\_

每天注射次數:  1次  2次  3次  4次  其他 \_\_\_\_\_

抽針使用之胰島素:

Actrapid HM  Protaphane HM  其他 \_\_\_\_\_

每天注射次數:  1次  2次  3次  4次  其他 \_\_\_\_\_

胰島素泵: 名稱 \_\_\_\_\_  
每天注射次數:  1次  2次  3次  4次  其他 \_\_\_\_\_

7.2 正使用口服胰島素藥物名稱:  Metformin  其他 \_\_\_\_\_

7.3 正服用其他藥物之名稱: \_\_\_\_\_

--- 請轉後頁 ---

7.4 對糖尿病之自我照顧:

7.4.1 我會:  計算食物之卡路里  
 閱讀食物上有關卡路里及糖份含量標籤

我正食用:  無糖食品, 如: \_\_\_\_\_  
我正進食特別餐: \_\_\_\_\_

7.4.2 - 當我血糖低時, 我感到:

饑餓

頭暈  
 疲倦  
 頭痛  
 面色蒼白  
 出汗  
 情緒不穩  
 發抖  
 其他: \_\_\_\_\_

- 於血糖低時, 我會使用之處理方法:

進飲果汁: 進飲之份量 \_\_\_\_\_ ml  
 進飲糖水: 進飲之份量 \_\_\_\_\_ ml  
 進食糖果: 進食 \_\_\_\_\_ 粒  
 進飲/食其他: 名稱 \_\_\_\_\_ 份量 \_\_\_\_\_

7.4.3 - 當我血糖高時, 我感到:

口渴  
 排小便較多  
 疲倦  
 情緒化  
 其他: \_\_\_\_\_

- 於血糖高時, 你的處理方法: \_\_\_\_\_

7.4.4 我知道患酮症之症狀:

嘔吐  氣促  腹痛  其他 \_\_\_\_\_

- 若我患酮症時之處理: \_\_\_\_\_

7.4.5 當我患病時, 我會:

檢驗血糖  若血糖 > 15mmol/l, 會檢驗小便含酮情況  
 若小便含酮, 會致電糖尿中心或就診急症室

7.5 當作劇烈運動時, 我會視乎運動量:

加糖份:  1份  2份  3份  
 減胰島素

7.6 你上次抽血作HbA1C之數值: \_\_\_\_\_ mmol/L 日期 \_\_\_\_\_

7.7 你上次作眼科檢查之日期: \_\_\_\_\_

7.8 你上次之血壓: \_\_\_\_\_ mmHg 日期: \_\_\_\_\_

7.9 你最近檢驗之小便是否含旦白:  是  否  
需服食 ACEI:  需要  不需要

7.10 參加糖尿支援小組: 有  名稱: \_\_\_\_\_ 沒有

--- 完 ---

# Feedback from **Adolescents and Parents** receiving Transition Care

- Period: 1/1/2011 to 23/2/2018
- 68 & 107 questionnaires from patients & parents respectively.
- Felt transitional care important:
  - 39 questionnaires from patients (57%)
  - & 60 from parents (56%)



## Feedback from **Adolescents** receiving Transition Care

- Reasons from adolescent patients who **felt important:**
  1. Worried about the adjustment in adult service
  2. The transition care increases their self understanding
  3. The care arouses them to be more concerned about their disease management
  4. Knew more about details of transition arrangement





## Feedback from **Parents** of Adolescents receiving Transition Care

- Reasons from parents who **felt important:**
  1. Worried about their children's adjustment in adult service
  2. Thought that their children needed to prepare well and cope with the change
  3. The care can help their children increase in self-awareness.



## Evaluation (Adolescents)– Usefulness of Tools

### 1) My Health Passport, 2) Young Person Questionnaire

- 90 (84%) questionnaires from patients answered that My Health Passport was useful.
- 105 (98%) questionnaires from patients answered that Young Person Questionnaire was useful.



## Evaluation (Parents) – Usefulness of Tools:

### 1) My Health Passport, 2) Young Person Questionnaire, 3) Parent Questionnaire

- 58 (85%) questionnaires from parents answered that **My Health Passport** was useful.
- 54 (79%) questionnaires from parents answered that **Young Person Questionnaire** was useful.
- 63 (93%) questionnaires from parents answered that **Parent Questionnaire** was useful.



# 2. Peer Group Support :Background

- Adolescents with different chronic illnesses always face the same challenges.
- This peer group provides a platform for them to develop positive connections with other youths and skills in similar circumstances through group interactions.
- Program in clinic days maximizes attendance.



# Objectives of Peer Group Support:

- To empower self-management of chronic illnesses.
- To develop social and peer support amongst adolescents through group activities.
- To equip adolescents with skills to take up transition to adult service.



# Target Group:

- Aged 12 to 18 adolescents with Diabetes Mellitus managed in the Department without impaired intelligence.
- Parents are also invited to join the group with some topics, e.g. Stress management.





# Venue, Date & Time:

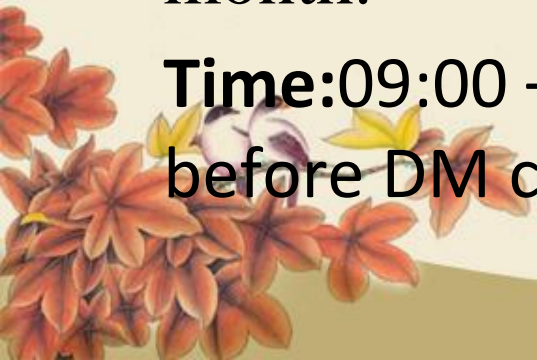
## Venue:

Diabetes Ambulatory  
Care Center.

## Date:

Starting from 17/11/2017  
DM clinic, once per  
month.

**Time:** 09:00 – 10:30  
before DM clinic.



# Content of Peer Group Support:

- Simple games are led by designated group members.
- Specific and focused short talks by working group members.
- Group activities & individual counselling.



# Specific and focused short talks:

- Stress management
- Medication
- Independence
- Socialization
- Body image
- Friends
- School
- Parents
- Discomfort
- Anger
- Teasing
- Fears
- Hospital & staff
- The future
- Leaving paediatrics to go to adult care



## Evaluation questionnaires: Feedbacks by **12 patients**

(From 0 to 10 scores)

Below results: **Score > 6**

1. 你享受參加這小組活動嗎? 9 (75%)
2. 你覺得參加這小組活動對你有幫助嗎? 11 (92%)
3. 你覺得參加這小組活動能助你去除負面的情緒嗎? 9 (75%)
4. 你覺得參加這小組活動能助你照顧和管理好自己的疾病? 8 (67%)
5. 你覺得參加這小組活動能助你對生活有正面的看法? 10 (83%)
6. 你能透過參加這小組活動而認識朋友? 7 (58%)
7. 你能透過參加這小組活動學到解決困難的方法? 10 (83%)
8. 你覺得參加這小組活動能助你了解自己? 10 (83%)
9. 你覺得參加這小組活動能助你增強自信心? 9 (75%)
10. 你對這小組活動若有其他意見: 17歲兒回答應增加遊戲以增加趣味性



### 3. Post-transition phone evaluation: Satisfaction Survey

## Opinion from adolescent diabetic patients

- Method
  - Phone interview 30/1/2014 to 5/2/2014
- Five questions:
  1. Understanding of disease (DM)
  2. Confidence in managing disease
  3. Medication adherence and knowledge
  4. Being independent e.g. attending or making appointment
  5. Satisfaction on the transitional care



# Post-transition phone evaluation: Satisfaction Survey

## Opinion from adolescent diabetic patients

- Five point Likert Scale
- (5-very good, 4-good, 3-neutral, 2-not good, 1-bad)
- 6 DM patients:
  - A. Understanding of disease
    - 88% (good to very good)
  - B. Confidence in managing disease
    - 83% (good to very good)
  - C. Medication adherence and knowledge
    - 83% (good to very good)
  - D. Being independent
    - 67% (good to very good)
  - E. Satisfaction on the transitional care
    - 83% (good to very good)





# Conclusion

- Transitional care should start early.
- Shared Management Model is used in this program with patients' progressive participation in health management.
- Ongoing assessment & counselling by various TOOLS & role play.
- About 80% or above patients & parents thought the TOOLS were useful in the feedback.



# Conclusion

- Peer support group was introduced to equip adolescents with skills and knowledge. Feedbacks were positive.
- A post-transition phone evaluation to the patients was conducted in 2014. Results were positive.

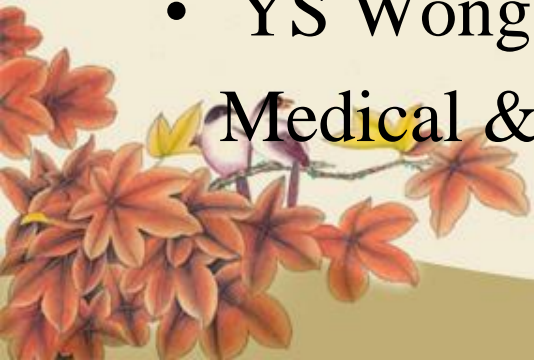


**“Transitional Care” bridge the gap of the adolescents with chronic illnesses from adolescence to adulthood**



# Acknowledgement

- WK Cheung, WP Ma, ML Yeung, SH Ng, TY Tam, SH Yeung , WY Leung , Ann Wu, PK Ma, Dr. P Cheung,  
Paediatric & Adolescent Medicine Department.
- MP Ng, M Mok,  
Diabetes Ambulatory Care Center.
- YS Wong, Dr. SY Lin,  
Medical & Geriatric Department.



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- [www.sickkids.ca/good2go/](http://www.sickkids.ca/good2go/)





THANK  
YOU!

The text 'THANK YOU!' is rendered in a decorative, stylized font. 'THANK' is in dark blue, 'YOU!' is in green, and the exclamation point is in purple. Three flowers are integrated into the design: a large red flower with a white center on the left, a smaller orange flower on the right, and a purple flower on the right. The entire graphic is set against a white background.