

出國報告（出國類別：進修）

兒童心臟病照護及緩和醫療介入時機

服務機關：國立臺灣大學醫學院附設醫院

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壹、摘要

先天性心臟病因創新手術術式及使用高科技體外維生系統儀器照顧技術之精進，突破過去心臟手術所需體重及年齡的限制，使病童存活率提升。此次於 2017 年 12 月 28 日至 2018 年 6 月 25 日前後各三個月主要赴英國倫敦 Royal Brompton Hospital 及比利時魯汶大學醫院 Gasthuisberg 學習先天性心臟病兒童重症照顧、心臟手術前後照顧、過渡期照顧（transition care）及兒童緩和安寧醫療實務操作，並至比利時魯汶大學進修先天性心臟病相關議題研究。建議短程目標可將兒童早期警訊系統、自我管理藥物（Self-administration of medication）及經修正後調整為適合國內臨床實務運用，建立有組織的兒童緩和醫療照顧；遠程目標可放於有整體性照顧的兒童至成人期轉渡期照顧。

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貳、本文

一、進修目的

隨著醫療科技的進步及密集照護下，慢性病病童存活率逐年提升；而先天性心臟病由過去存活率 50%提高至 95%以上，主要原因是手術及照護方式的精進。在醫療方面，本院心血管醫療團隊持續不斷的創新手術術式，挑戰世界少見的先天性心臟病診斷，突破過去開心手術體重及年齡的限制，但因如此，在手術過程中，因心肌缺血而使用體外維生系統（包括葉克膜或心室輔助器）的機會增加，目的是要爭取時間等待心血管循環系統恢復。心臟手術術後即移至加護病房照護，使護理照護上的複雜性漸增、壓力及照護能力備受挑戰。體外維生系統在急重症加護單位扮演一個重要角色，不但需要高度的專業與豐富經驗，更需要大量的人力和成本投入照顧，才能使其發揮最大成效，因此，隨著醫療的精進，研究兒童急重症照護及體外維生系統的護理照護品質上繼續提升及改善的必要性是不容小覷的，才能使其高成本的健保支出下，急重症兒童的存活率及其後續生活品質有其相對的價值。

但在如此疾病嚴重的狀況下使用體外維生系統，爭取時間來進行積極治療，對於治療方針都是全力積極維持病童生命徵象為目的。統計 1994 年到 2014 年院內心臟病術後裝置葉克膜的病童（<18 歲）平均一年約有 30-40 人次，存活率約 45%，將近六成的死亡率，放置天數小於 7 天的存活率 47%隨放置天數拉長到大於 60 天存活率降至 22.2%。除本身心臟疾患外，裝置體外維生系統的時

間及合併症也影響病童的存活率及其後續健康狀況。目前葉克膜使用期間在照護病童方面都是給予父母解釋當下的病情狀況，因為無法預期在嚴重且緊急的情況下病情變化方向會是如何，往往病童裝置葉克膜開始有溶血或血栓情況發生而頻繁更換葉克膜管路且出現併發症，如：顱內出血、四肢末梢開始缺血壞死或肝腎衰竭才跟父母談論後續病情可能漸趨下坡，接踵而來一連串病情的噩耗，延長死亡過程。目前醫療團隊除了對病童在醫療上有處置外，其餘應協助支持家庭渡過危機的介入甚少。對於無法確定病程走向且目前家庭少子化，父母面臨將可能會失去一個孩子帶來的衝擊影響家庭整體。住在加護病房期間是進行積極治療的階段，但何時介入緩和醫療才是適當時機也是應該被重視和關心的。

反觀英國是第一個成立兒童安寧緩和的國家，兒童安寧緩和療護並不像成人是與死亡過程相關，而是在慢性疾病及生命受威脅的疾病診斷初期即給予介入協助病童及家庭面臨複雜的醫療問題，使病童接受急重症醫療積極治療的同時也一併給予緩和醫療。此次進修目的：(一)在英國最大兒童心臟專科醫院學習先天性心臟病童連續性照護及臨床實證研究；(二)學習當生命受威脅的心臟病童在積極治療情況下如何處理、運用相關的資源等方面來一併進行兒童緩和醫療；(三)瞭解歐洲國家護理教育、研究發展及如何落實於實際面。將相關概念帶回本院分享並修正落實在實際臨床照護上。

二、進修過程

(一) NHS Royal Brompton Hospital 概況

Royal Brompton & Harefield NHS Foundation Trust 包括 Royal Brompton Hospital 位於倫敦市中心及 Royal Harefield Hospital 提供倫敦郊區外成人、胸手術、移植及心室輔助器之照護，為知名心臟專科醫院，自歐洲各國前往見習之醫事人員人數眾多，包括愛爾蘭、德國、西班牙及義大利；倫敦帝國大學（Imperial College, London）為其合作大學以進行心肺疾病之國際研究。目前倫敦地區共有五間被國家醫療服務體系（National Health Service, NHS）England 核可能夠進行兒童心臟手術，其中，Royal Brompton Hospital 建立於 1847 年，為提供英國國內及歐洲地區之心、肺疾病治療最大的專科醫療服務，醫療費用及醫材大部分由 NHS 支付，民眾就醫只需付極少的部分負擔。此次進修主題為兒童心臟病照護，故選擇一年收治 500 位病童的 Royal Brompton Hospital 為主要進修地點。根據見習目標除至主要進修醫院了解先天性心臟病童急重症照顧之外，負責此次進修安排的護理教育者（clinical educator）聯絡幾間心臟病兒童照護相關合作醫院進而了解英國對於心臟病童的全面及連續性照護（如表一）

表一 進修參訪醫院及機構

日期	地點	目的
2018/1/15	Broomfield outreach clinic	心臟病童郊區地區門診
2018/1/29	Queen Charlotte's and Chelsea Hospital	先天性心臟病胎兒門診
2018/2/5 2018/3/27	Great Ormond Street Hospital	兒童心臟移植及 Berlin heart 照護、兒童緩和醫療團隊會議

2018/3/15	St. Thomas' Hospital	成人心臟病轉渡門診 (Transition process)
2018/3/28	Shooting star in Hampton	兒童安寧機構



圖 1 Royal Brompton Hospital 外觀

Royal Brompton Hospital 有 312 床，超過 1600 位工作人員、五間手術房及四間心導管室，設有手術室、加護單位、胸腔科、心臟科、兒童病房及兒童加護病房等六個單位，此外設有心臟型態單位 (cardiac morphology) 擺設許多先天心臟疾患之心臟標本並開設一系列心臟型態學課程以提供院內醫事人員學習。此次進修單位為兒科病房及兒童加護病房。兒科分為病房、兒童 high dependency unit (PHDU)及兒童加護病房三部分，專收治 0-16 歲心臟及呼吸疾患之病童，由一位護理長 (Matron) 負責管理上述三單位，英國每週工時 37.5 小時，每周工作為 3-4 天，一班別為 12 小時 07:45-19:45、19:45-07:45，分白班及夜班。設有護佐 (health care assistants) 以協助 bedside nurses 處理非直接接觸病人之事務，包括:整理床旁、廚房及洗手間環境、協助病人家屬點餐、新病人環境介紹、協助完成入院紀錄、轉床、出院床環境整理、治療車用物整理及維持、治療室環

境、藥物有無過期之檢查、協助執行血液氣體分析檢查。下列以三個單位分別描述:

兒科病房共有 37 床，六人房 1 間、五人房 3 間、四人房 1 間，單人房 6 間、睡眠檢查室 4 間、觀察室一間共 4 床，設置一位書記，一位專科護理師

(Advance nurse practitioner, ANP)，護理師共 80 人。在照顧心臟疾患病童護病比為 1:3、照顧呼吸道疾患病童(囊狀纖維化及氣喘等)護病比為 1:4。

每班有一位 Nurse in Charge 負責跟查房、追蹤主治醫師查房後醫囑開立及執行情形、床位協調及協助護理師處理事務；一位 nurse runner 協助 Charge Nurse。兒科單位設置一位 bed manager 每日早晨醫師查房完後與兒科病房及加護病房 Charge Nurse 共同協調進行床位調整。每位病童在入院時皆須留取鼻腔及鼠蹊部檢體檢驗有無受抗藥性金黃色葡萄球菌感染。



圖 2 兒科病房護理站

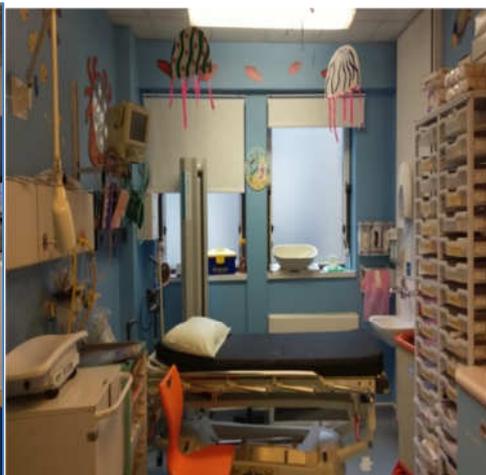


圖 3 兒科病房治療室



圖 4 病人床邊藥物櫃（上鎖） 圖 5 急救車及電擊器（上鎖）

兒科病房紀錄目前電子上線只有給藥紀錄，其餘護理及醫療紀錄等仍採用書面方式記錄。*Bedside pediatric early warning system (BPEWS)*為目前採用紀錄病童生命徵象之表單提早辨識病童病情惡化之趨勢藉由心跳、收縮壓、呼吸速率、血氧、使用氧療、呼吸功和微血管充填時間七項臨床指標，分年齡層及以0,1,2,4 方式計分（a total BPEWS score ranged from 0 to 26）分數越高代表病情變差，藉由分數指標可以評估醫療人員對病童觀察之頻率，如 Q4H 縮短至 Q15min（如圖六）。目前廣泛在歐洲各國研究並使用其對於第一線醫療人員及護理師之溝通和及早偵測到病童病情變化（附件一）。

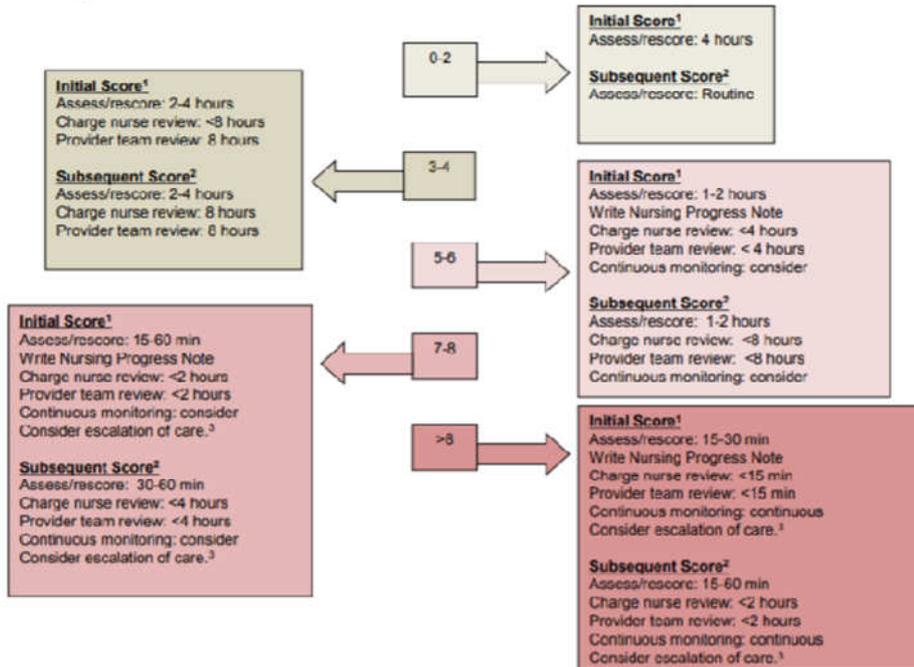


圖 6 Bedside pediatric early warning system 經分數換算後介入措施

品質管理

在兒童壓瘡評估使用「Pediatric pressure ulcer risk evaluation tool and action plan」與目前本院使用的 Braden 壓瘡評估不同，在此評估中增加 weight、skin、capillary refill、oxygen saturations、surgery、medication 及 special risks（附件二）。每班護理師皆須評估有無發生壓瘡、計算總分（total score 10-40）並記錄於病歷上。如果病童有壓瘡發生則須在護理紀錄上註記及完成 body map，並在每周發布壓瘡發生率品管報告及進行檢討，每周兩次重新進行壓瘡傷口評估並採取 very high risk action。在預防壓瘡措施上，使用了氣墊床（repose air cushion）、各種尺寸的 pressure reducing pads 放置在導管與皮膚接觸或骨突易受壓處。經鼻氣管內管、鼻胃管放置處受壓觸泛紅則使用蜂膠產品預防壓瘡產生或是促進壓瘡傷口癒合，下圖為預防壓瘡發生之相關醫療用品。



圖 7 Cushion 床



圖 8 Pressure reducing pads



圖 9 蜂膠

給藥方面

在兒童給藥方面不論口服（furosemide、aldactone 及 esomeprazole 等）或注射藥，所有給藥皆採兩位護理師共同核對之制度，兩人共同執行三讀五對，在兒科藥物劑量需要計算方面也採各自獨立計算後再雙人覆核於電腦給藥系統；與本院部分藥物執行雙人核對有部分差異。本院因經過 JCI 評鑑，在給藥方面落實「親視服藥」並指導用藥方式及食物藥物交互作用注意事項；此次參訪醫院不論在成人或是兒科病房單位皆推行「Self-administration of medication」，目的在增加照顧者或病人了解自身用藥狀況跟對藥物的認知，進而能對返家後給藥之能力及對自身健康之責任，不強迫參加，如果選擇參加則簽妥 self-administration of medication 同意書，由護理師或藥師進行自行給藥能力之評估並提醒藥物辨識、用藥目的及可能的副作用等。根據評估將能力區分為三級：Level 1 由護理師將藥物拿出來但由照顧者執行給藥；Level 2 由護理師提醒給藥時間，由家屬自行取藥給藥，必要時由護理師在旁進行觀察；Level 3 全權由照顧者進行給藥，給

藥完畢照顧者在病歷上簽名，能力由住院時間長短可評估做調整，管制藥、需冷藏、靜脈注射藥等則不在自行給藥的範圍內，只有放在病人床旁藥物櫃內藥物才適合進行，如照顧者給錯劑量情況發生或照顧者無法擔負給藥任務，則須立即告知醫療人員處理並由護理師給藥（附件三）。

管路照顧

兒科最令護理師感到棘手的是如何評估周邊靜脈管路留置針在何種狀況下應該拔除。在此見習單位每班使用 Visual Infusion Phlebitis score（VIP）來做為依據，分數 0-5 分，分數越高代表需要即刻處理。運用此統一量表以測量分級和嚴重程度讓護理師及家屬之間溝通可有判斷依據（表二）。在執行放置留置針前，為了讓病童疼痛感減低則使用 local anesthetic spray 或 Emla cream。



圖 10 氣管內管固定

表二 Visual Infusion Phlebitis score- (VIP, Jackson 1998)

Observation	Score	Action
Iv site appears healthy	0	No signs of phlebitis->observe cannula
One of the following is evident: ● Slight pain near iv site or ● Slight redness near iv site	1	Possible first signs of phlebitis-> observe cannula
Two of the following is evident: Pain at iv site 、erythema 、swelling	2	Early stages of phlebitis->resite cannula
All of the following signs are evident: Pain along the path of the cannula 、erythema 、induration	3	Medium stages of phlebitis -> resite cannula 、 consider treatment
All of the following signs are evident & extensive: Pain along the path of the cannula 、erythema 、induration 、palpable venous cord	4	Advanced stage of phlebitis or thrombophlebitis-> resite cannula 、 consider treatment
All of the following signs are evident & extensive: Pain along the path of the cannula 、erythema 、induration 、palpable venous cord 、pyrexia	5	Advanced stage of thrombophlebitis-> initiate treatment 、 resite treatment

PHDU 部分共 8 床，收治長期需要使用非侵入性呼吸器 CPAP、BiPAP 或注射前列腺素 E1（Prostaglandin E1）、強心劑之病童，護病比為 1:2。觀察進修單位的臨床護理工作內容大多與本院相似。



圖 11 遊戲室

加護病房照顧

加護病房收治行心胸手術後或從外院轉入病童共 20 床，護理師共 60 人，病房設置為四人一間共 4 間房，如病童有特殊需求或需要隔離者則入住單人病房，共 4 間。進行特殊治療包括血液透析、一氧化氮及葉克膜。加護病房護病比為 1:1，如:病童裝置葉克膜則護病比為 2:1。每間病房內皆備有急救車及電擊器，在急救車旁皆有掛牌提醒急救時醫療人員角色功能，病人床邊皆貼有急救藥物建議劑量表。



圖 12 加護病房內關胸骨手術



圖 13 放置葉克膜病童



圖 14 葉克膜



圖 15 術後加護病房照護



圖 16 小兒集尿袋及胸腔引流瓶

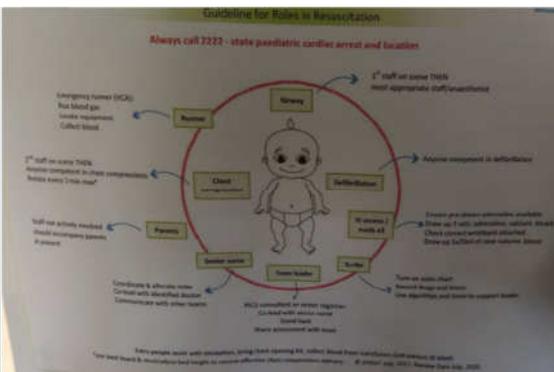


圖 17 提醒急救時醫療人員角色功能

Emergency Drug Calculator charlie Salter / 4044235 Weight [kg] 3.5

Adrenaline 1 : 10,000 IV [0.1 ml/kg] (500 mcg/5ml)	35 mcg	0.4 ml
Adenosine IV [0.1mg/kg] (3 mg/1ml)	0.4 mg	0.1 ml
Amiodarone IV [5 mg/kg] (50 mg/1ml)	18 mg	0.4 ml
Atropine IV [20 mcg/kg] (600 mcg/1ml)	100 mcg	0.2 ml
Na⁺ bicarbonate 8.4% IV [1 mmol/kg] (10 mmol/12ml)	3.5 mmol	3.5 ml
Ca⁺⁺ gluconate 10% IV [0.5 ml/kg] (2.25 mmol/10ml)	0.4 mmol	1.8 ml
Mg⁺⁺ sulphate 50% IV [0.1 ml/kg] (500 mg/1ml)	175 mg	0.4 ml
Metaraminol IV [10 mcg/kg] (10 mg/1ml) * dilute 1ml in 3ml NaCl 0.9% and reconstitute 1ml of this solution in 3ml NaCl 0.9% (100 mcg/1ml)	35 mcg	0.4 ml

Flowchart:
 Unresponsive? Not breathing or only occasional gasps → CPR (3 initial breaths then 15:2) → Assess rhythm → Shockable (VF / Pulseless VT) → 1 Shock 4J/kg → Return of spontaneous circulation → Reversible causes (Hypoxia, Hypovolaemia, Hypothermia, Hypothesia, Tension pneumothorax, Toxins, Tarponade - cardiac, Thyrotoxicosis) → Immediately resume CPR for 2 min → Return of spontaneous circulation.
 Non-Shockable (PEA / Asystole) → Immediately resume CPR for 2 min → Return of spontaneous circulation.

During CPR:
 • Ensure high-quality CPR: rate, depth, recoil
 • Plan actions before interrupting CPR
 • Give oxygen
 • Vascular access (Intraosseous, Intraosseous)
 • Give adrenaline every 3-5 min
 • Consider advanced airway and capnography
 • Continue chest compressions when advanced airway in place
 • Correct reversible causes

Reversible Causes:
 • Hypoxia
 • Hypovolaemia
 • Hypothermia
 • Hypothesia
 • Tension pneumothorax
 • Toxins
 • Tarponade - cardiac
 • Thyrotoxicosis

Defibrillation, synchronized [1 J/kg]	4 J
Defibrillation, asynchron [4 J/kg]	14 J

圖 18 急救藥單及流程

此次見習著重於裝置**葉克膜後兒童之照護**，見習單位由兩位護理師共同照護，一位為 baby nurse，一位則為 ECMO nurse。Baby nurse 主要負責照顧病嬰及藥物泡製（包含急救藥物預抽）、以 insulin 控制血糖值須維持在 210mg/dL (12mmol/L)以下、每小時 milking chest tube 進行記錄 blood loss > 10ml/kg/hr 則需要報告，並以血漿製品 ml by ml 方式給予。照顧裝置葉克膜病童護理重點包括：維持呼吸道功能及預防院內肺炎、觀察心血管功能、維持皮膚組織完整性、止痛及意識觀察、對於家屬焦慮之支持、腸胃道功能之維持及凝血功能狀況之觀察。因心臟術後易有大量出血情況發生，也有血品輸注準則以利護理師參考。在維持中心靜脈導管及動脈導管通暢及監測予各使用 0.5ml/hr 生理食鹽水 keep line。ECMO nurse 為維持 ECMO 正常運轉，包括執行凝血功能時間檢測、依 protocol 調整 Heparin 劑量（附件四）、每小時用手電筒確認動靜脈導管有無血栓產生、不穩定病人則進行每四小時抽血球生化凝血功能等、每小時執行動靜脈血液氣體分析及每小時紀錄氧合器系統壓力變化。心臟手術後危急之病童在監測儀器上，增加 cerebral oximeter 以監測顱內氧合變化。抽痰拍痰由物理治療師一天兩次至病床邊進行，護理師只在需要時輕柔拍或是抽吸痰液。

床邊關胸預抽急救藥物包括 Epinephrine, NaHCO₃, atropine, voluven 數支，有兩位手術室護理師負責刷手及流動，麻醉醫師及至少兩位 ICU 護理師在場執行紀錄部分。Heparin infusion 則是在手術前兩小時停止輸注，手術進行前需要 time out 在場人員要一一報自己的名字和職稱，由主護紀錄於 ICIA 系統裡，術後也

需要更換胸腔引流瓶。加護病房內心臟術後病童的靜脈營養攝取或腸胃道營養攝取皆有準則可以依循；靜脈營養攝取（全靜脈營養及脂質）需要根據前日總輸注量及心臟病童手術後初期被限制水分（第一天 60ml/kg、第二天 70ml/kg、第三天 80ml/kg，之後兒童每日水分攝取量以 100、50、20 計算），運用公式由護理師來計算當日每小時輸注量，與本院由醫師或專科護理師計算所需熱量後開立醫囑作法相異。給予鼻胃管灌食也根據年齡層不同有不同的 protocol，與本院在初始餵食病嬰皆用 20-30ml D5W 餵食兩餐之作法相異（附件五）。

Clinical Nurse Specialist

1. Children' s cardiac care team

Cardiac care team 由 clinical nurse specialist 組成包括：fetal cardiac care、children' s cardiac care、electrophysiology、transition care。Congenital care team 於 2001 年 2 位 CNS 到至今由一位 leader nurse (1993 年執業於兒科心臟科服務，業務內容 50%行政 50%兼 fetal cardiac care CNS)帶領 3 位 fetal cardiac care clinical nurse specialist、4 位 children' s cardiac care clinical specialist、2 位 transition care clinical nurse specialist 及 1 位 kawasaki nurse specialist。Children' s cardiac care clinical specialist 在疾病診斷到出院給予孩童及家庭支持，甚至 transition 到成年期，服務包含醫院、社區，必要時提供家裡及學校訪視，聯絡 health visitor (NHS)、校護及社區護理師共同支持這個家庭，並參與 network hospital 心臟科醫師門診以了解孩童轉診及獲得疾病消息的情形，也扮演專家角色給予地區醫院

專業諮詢。也是扮演青少年到成人 transition process 的關鍵角色。術前詳細說明手術及了解病家支持情緒。

Fetal cardiac care 由 Royal Brompton Hospital 支援倫敦附近有產科門診之醫院，協助產前被診斷胎兒患有先天性心臟病之孕婦。由胎兒心臟科醫師行超音波診斷之後告知孕婦，後續如：胎兒診斷疾病的細項、出生後的情況、將進行之治療手術計畫、嬰兒出生後將會如何被轉送至其他專門治療先天性心臟病醫院、母乳收集或如何協助嬰兒進食、嬰兒將接受如何的長期追蹤計畫等皆由 fetal cardiac CNS 在諮詢室向準父母解釋，並給予指導手冊及 CNS 的聯絡電話（統計如嬰兒被診斷為左心室發育不全有 60%產婦決定中止妊娠）。2013 年開始舉行每個月第一個禮拜六將該月預計會生產的準父母集合至嬰兒出生後最終將被轉至的 Royal Brompton Hospital 進行 PICU、病房、哺乳室、監視器等環境介紹，並告知家屬嬰兒身上將會有那些傷口、管路及監視器等，提供那些生產後無法陪同嬰兒的媽媽們知道之後會碰到的情形。除此之外，fetal cardiac CNS 需要請 PICU 備床、告知 PICU 產婦將於何時生產、嬰兒將何時到達。嬰兒出生後業務轉交給 cardiac care CNS。

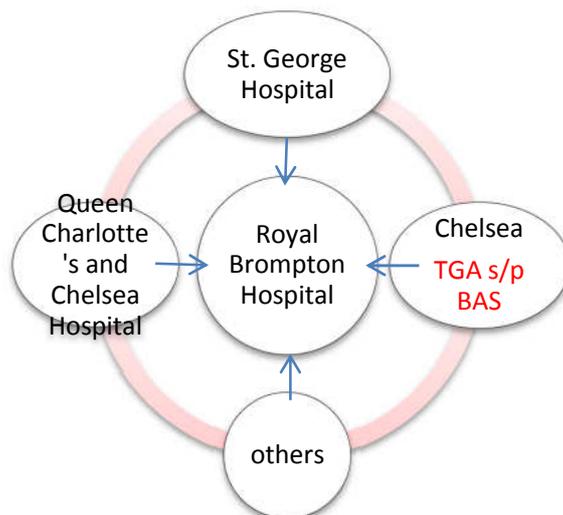


圖 19 Royal Brompton Hospital 合作醫院

Cardiac care clinic nurse specialist 除在門診給予已被診斷病童及家屬之疾病解釋、術前治療解釋、可能會使用的藥物、長期結果治療及情緒支持之外，在病童手術返家後再次複診（約 6-8 周）需要追蹤，當病童返校 CNS 則需要至學校與老師、校護進行會議討論與病童教育及疾病相關計畫，如：運動、血氧監測、血氧影響腦部智力方面之問題。並在病童可能進行下一次手術前（如：10 歲 TOF 可能會有瓣膜問題等）協助父母與心理師會談，病童則由 play specialist 藉由遊戲、繪本圖書、圖片或實際用具等，依據年齡使用病童能了解的語言向病童解釋手術過程、醒來之後身上會有那些管路是要幫助他恢復健康的。

Transition team 在門診會有 transition clinic 服務對象為 12-25 歲先天性心臟病患者，目的是要讓本來由父母照顧的病童，因年紀漸長轉渡至青少年及成人，要讓病患在這段時間了解自己的疾病及健康生活型態之重要性。病患來源皆由該院心臟科醫師轉至此門診，每位病童在這段轉渡至成人期間會在 transition

clinic 諮詢三次各一小時，並依據病患返心臟科門診時間來一同安排就醫及諮詢。

病童皆由父母帶至此門診與一位 transition team 中的 clinic nurse specialist 進行會談，以病童為主體、父母為輔，先了解是由哪位心臟科醫師轉診過來、preferred name、最近一次什麼原因看過家庭醫師、有無學習障礙、聽力身體活動失能狀態、主要照顧者是誰、詢問知道為何被轉至此進行諮詢、未來是否繼續念書或工作、在學校有興趣的科目、常進行的身體活動、未來想從事的職業、是否了解自己心臟疾病及曾經進行的手術、有無其他疾病及就醫狀況、目前藥物使用情形及過敏史、會害怕打針嗎?接受流感疫苗注射之情形、有無抽菸喝酒喝飲料咖啡因、能量飲料攝取情況、是否擔心自己心臟症狀、有無心悸胸痛、頭痛、活動喘之情形發生、刷牙次數及預防心內膜炎發生、健康保險旅遊保險討論、運動三餐飲食情況、生殖遺傳心臟病議題、家族心臟病情形、手足健康情形、同儕是否知道病童心臟情形、對自己身體心像感覺、目前有無心理健康方面之問題及告知滿 17 歲之後將轉至青少年先天性心臟病門診。CNS 先用圖片先向病童說明正常心臟構造及循環，再根據疾病診斷用 cardiac defect 圖片解釋之前手術之目的，每項問題目的在評估病童對自身的了解，針對每項問題或回答 CNS 皆闡述注意事項的原因及給予目前生活型態調整之建議。每次諮詢診間隔至少一年，在第二三次皆是圍繞在這些議題，以增強病童的知能，諮詢結果皆會回覆給心臟科醫師、家庭醫師、health visitor 及學校，當病童已經超過 17 歲被轉至青少年門診時，transition nurse specialist 亦須至青少年門診甚至成人門診完成

此項諮詢（附件六）。

心臟移植病童照護

Great Ormond Street Hospital 為英國最大的 400 床兒童醫院（小於 16 歲）成立於 1852 年，共有 63 個專科及分為 35 病房單位，為負責兒童心臟移植中心之一。此次一日行程為參觀手術室、心臟科病房及心臟加護病房（Flamingo ward），主要是了解兒童心臟移植照顧及 Berlin heart - bridge to transplant。1988 年開始第一例兒童心臟移植，目前由歐洲各地轉院每年有 20-30 例兒童心臟移植手術個案，在進入移植 waiting list 時移植小組即給予共 116 頁的心臟移植手冊告知家屬和病童接下來會面臨到的一連串檢查及過程，從接受移植後照顧者的心路歷程、術前評估、手術方式、照護場所等一連串治療過程到返家及後與照顧及後遺症等皆有清楚描寫。與本院相異之處為，該院經過心臟手術後病童在加護病房時期住正壓隔離病房，轉至一般病房則入住單人房。



圖 20 兒童心臟科病房及加護單位



圖 21 指紋感應藥庫系統

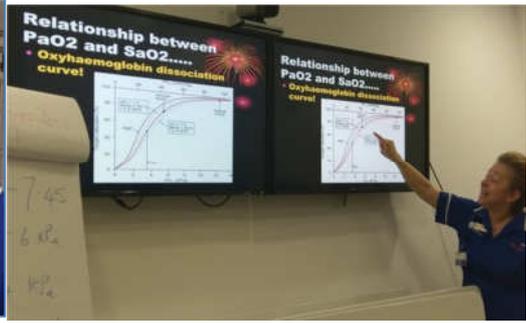


圖 22 Clinic educator 替新進護理師上課

兒童緩和安寧照護

安寧緩和起源於英國，剛開始發展為提供成人生命末期照護服務，因服務需求逐漸擴大而擴展於有需求的兒童及青少年族群（0-17 歲），1982 年第一家 children' s hospice 為 Helen house。目前服務範圍包括在醫院、安寧照護機構或家中提供照護。此次見習兒童緩和安寧醫療場所在 Royal Brompton Hospital（服務對象針對住院病童）、Great Ormond street hospital (in London)及 Shooting Star Chase house Children Hospice (in Hampton)。

針對左心室發育不全之心臟病童在第一階段手術到完成第二階段手術期間死亡率約 20%，因此，Royal Brompton Hospital 進行照顧方式是在病嬰完成第二階段手術後才允准出院，該院病童平均住院天數約三個月，最長到兩年，統計死亡率為 14%。對於超長住院病童照顧，由兒科護理師組成 complex care team 分三大組，針對病童住院期間大於三周以上會製作一本「All about me」放置在病床旁，紀錄內容包括照顧病童的醫療人員姓名職稱、家屬成員名字聯絡方式、家庭樹、病童照護計畫、雙方溝通事項及病童的作息（可以書寫病童的習性作息小名）以方便醫療人員與家屬間的溝通。

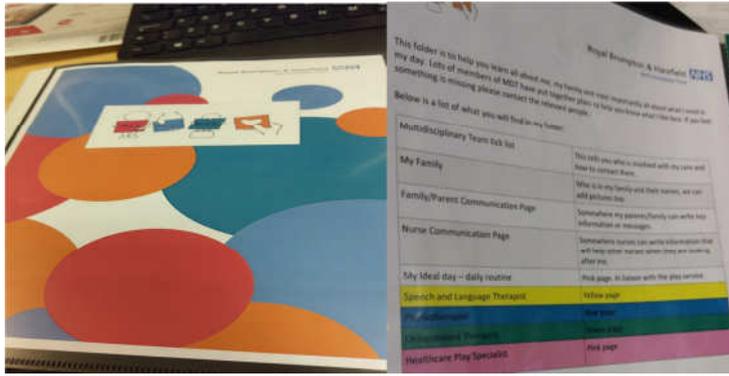


圖 23 All about me 手冊

每周三下午兒科病房及加護病房進行 compassion and liaison multidisciplinary team meeting (CALM meeting) (包含宗教師、資深護理師、護理長、palliative team nurse、心理師、資深 play specialist、職能治療師、社工師但不包含醫師) 十多位成員針對病童治療計畫 (包含了解負責治療的 picu 醫師、手術醫師、出院計畫由哪位 CNS 負責) 和目標及每位專業人員與家屬接觸後了解可能需要協助之部分進行討論。該院 pediatric care team 為 non-designated model 為護理師兼任兒童緩和醫療照護護理師、緩和醫療照護醫師為 picu 醫師兼任。緩和醫療照護護理師藉由此會議中了解哪些病童為潛在需要緩和醫療服務的對象，在 picu sister 暨兒童緩和醫療照護師 Anja Kollmann 表示在目前該院納入兒童心臟病診斷對象包括需要經過單一心室循環手術之左心室發育不全、心衰竭經過換心手術及放置葉克膜之病童。根據英國國家衛生研究院和卓越保健 (National Institute for Health and Care Excellence, NICE) 準則之 End of life care for infants, children and young people with life-limiting conditions: planning and management 為基礎，聯合其他家醫療院所及社區安寧機構以家庭為中心提供緩和安寧照顧支持病童及其家庭，強調在生命限制的疾病治療過程中，緩和醫療照顧及治療是呈現變動關係，

因此也需要 parallel planning 希望在最病情差的狀況有一個最好的計畫「hope for the best but plan for the worst」，將病童、家屬、手足甚至病童最親密的朋友共同納入。Anja 表示向家屬提出緩和安寧照護計畫其實很不容易，通常需要醫療團隊有初步共識，過程中團隊間可能也會有爭執但都需要協調和討論，在家屬困難決定或不願意談論時，保留時間讓家屬成員進行討論。所有照護計畫皆紀錄於病歷且不與不急救同意書混淆：

第一步:先適當告知病情及代表之意義。

第二步:由一個主要負責醫師或是 palliative care nurse 單一管道，解釋照護需求或討論病程後續、治療方針、照護地點，討論信仰、價值、看法或感受。準備未來將面臨的困難處及合併症。

第三步:將照護計畫分享給相關照顧人員，如:家庭醫師、主治醫師、護理團隊、安寧機構、學校、喘息照顧服務機構等，並定時更新照護計畫及急救計畫。

兒童緩和醫療照護團隊目前提供病童及家庭支持、家庭會議、進階照護計畫（advanced care plan）、生命末期照護（end of life plan）、教育和支持醫療人員。其中，進階照護計畫內容為整合其他家兒童醫院網路共同製成，包含病童基本資料、主要照護者、家庭樹、計畫時間及下次審視時間、病童家庭成員及其他重要關係人期望（希望接受照護地點:醫院、家中或緩和安寧機構;症狀治療;參與計畫者及靈性文化方面）、病情診斷及主要問題、社交人際問題、特殊治療計畫、life threatening event 計畫、器官捐贈意願、同意計畫之醫師（lead

clinician) 及家屬 (parental responsibility)、24 小時醫療緊急連絡電話、如果小孩過世需要連絡之人員、心肺功能停止時採取之計畫 (附件七)。照護計畫完成後副本寄給家屬、相關醫事人員、學校或社福單位，整本即存檔於病歷。對於哀傷支持 (bereavement support) 醫院每年十月舉辦茶會，用電話或邀請函方式邀集前一年過世病童的家屬，家屬可以寫詩歌或音樂、由醫院準備氣球讓家屬共同施放至天際來懷念病童。

臨終接受照顧場所包含安寧照護機構，此次參訪 Shooting Star Chase in Hampton 照護對象為 0-21 歲病童生命末期照顧至哀傷服務，提供到府、日間照護、症狀治療及喘息服務 (一年 12 晚) 數日至數年的情緒支持和照護環境;收案條件須符合兒童安寧機構協會 the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)四項條件中其中一項。機構在 1995 年成立，目前已有兩個院區。根據機構統計每年 1/10 支出來至政府部門，其餘由 9/10 由各界募捐 (公益活動及慈善商店)，在照護支持方面，病童家庭不須付費。成員包含護理師、護佐、治療師、社工、諮詢師、志工等，由家庭醫師提供 on call 服務，由三家合作醫院之兒童緩和醫療醫師提供一周兩次到府診視病童及每周到該機構對於症狀治療需要改變的病童提供諮詢服務，機構尚有針對病童活動之樂器室、水療室、遊戲室、美術及手工藝室，香療按摩室提供病童家屬放鬆。見習期間參與了症狀治療門診及跨院區安寧緩和護理師、醫師多人視訊會議討論收案的病童病況決定是否結案及下次追蹤時間，統計收案時間

80%超過一年。在機構內過世之病童，房間外草原有一棵樹由喪子父母將星星掛在樹上，父母可以在每年孩子逝世當日回來懷念。針對孩子過世，需要時機構提供 cool blanket 讓孩子可以回家與父母待七天，每天由訪視員到家了解返家後狀況。



圖 24 Shooting Star hospice 外觀



圖 25 接待處

圖 26 安寧照護機構房間-兒童



圖 27 走廊



圖 28 共用餐廳



圖 29 花園



圖 30 紀念花園 (memory garden)



圖 31 青少年遊戲間



圖 32 嬰兒 cool blanket

護理教育與進階制度

英國護理階級分為 band1-band9，9 個階級，其中，band 8 還分為 band 8a、band 8b、band 8c 和 band 8d，根據臨床經驗及學歷作為依據。Band3-band4 為

Nurse assistant 主要協助新病人環境介紹、協助完成入院病人 admission paper work、鋪床、整理工作車、維持病人單位的整潔、確認病人藥物起訖時間、協助執行氣體分析檢查報告等。Band 5-6 為臨床護理師，Band 5 (Nurse staff) 為有學士學歷但無兒科/心臟科經驗之新進護理師，在病房期間最少在 6-9 個月完成 Level I (氧療、身評、BLS、感控、藥物劑量計算等技術) 和 Level II (照顧 HDU 病童、心電圖、電擊器等)；band 6 (sister nurse) 則要有 ICU rotation、整體性評估及 APLS 等 Level III 及 Level IV 需要照顧複雜性病人、複雜心電圖判讀處置、不穩定新生兒照護、病房內協調及專案管理等項目，類似國內目前 N1 到 N4 的進階制度。Senior nurse Liz Biggart 很熱情的分享醫院內護理師的工作職責及薪資階級，在工作職責如下表。在薪資規範有如台灣公務人員薪資呈現階梯式方式計算 (Band 5 有八階、Band 6 有九階、Band 7 有九階、Band 8 目前英國境內護理人員只到 8C)。

Band 5	大學畢業生、full time、尚無資格輪夜班 (可能超過一年)。
Band 6 (Nursing staff)	開始輪夜班、參與病房安全維護及專案執行、為 junior 護理師的導師負責指導臨床教學部分 (可擔任 Nurse educator 角色、類似本院臨床教師角色)。
Band 7 (Sisters)	需要高負責度、精通專科業務、領導角色、有碩士學位 (Clinical specialist nurse、senior educators)、替護理師上課 (cross training、clinical pathway education、EBN) (Nurse educator 角色類似本院 PGYN 導師角色)。

Band 8	分 ABCD 四級，8a (CNS, ANP) ;8b (Matron) ; 8c 為管理階級。
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(二)學術進修-KU Leuven university, Belgium 日期 2018.4.1-2018.6.25

此階段進修地點選擇比利時 KU Leuven 大學，學校位在魯汶是一個綜合大學城，也是歐洲國家頂尖學府之一，主要語言為荷蘭語但人民使用英文溝通程度亦高，吸引多國各領域短期進修高階人員學習實驗室實驗方法、統計方法等學習。此次進修單位為 Department of Public Health and Primary Care, Academic Centre for Nursing and Midwifery 主要指導教授為 Philip Moons 教授，具有急診及心臟加護病房之臨床經驗，主要研究領域為 Congenital heart disease transition care from adolescent to adult care。課堂上課內容主要與博士班學生一起參與護理研究法、統計學及旁聽 seminar 及研討會前口頭報告預演 (Transition and transfer: A scoping review)，同時由 Philip Moons 教授指導學術研究文章之撰寫邏輯、組織能力及統計方式運用，進一步學習到科學學術文章寫作的思路及架構呈現，如何在文章中闡述原理 (selling point and rationale) 如何才能使讀者了解研究文章之學術價值。在閱讀文獻及撰寫討論過程中引發我對臨床重症護理人員在照顧病人上的問題研究之興趣，如何以目前有的病歷資料來調查並進行預測因子之分析，提供目前護理人員在臨床照顧心臟病童上可以提前偵測到手術進行後到加護病房照顧之兒童可能會面臨 chest re-exploration 的因素而有妥善事前準備，目前研究計畫「Factors of predicting within 48 hours urgency re-exploration in children

undergoing cardiac surgery」初步計畫正在撰寫中，期望返國提出具體研究案之申請。



圖 33 魯汶大學圖書館

除了學術上的課程參與外，在教授協助下也參觀了 **University Hospitals Leuven - campus Gasthuisberg**，此為大學醫院。在比利時有四個兒童加護病房分別兩個在布魯塞爾、一個根特及一個在魯汶。本次見習單位為 收治年紀 0-18 歲，偶爾也收治成人術後病人，與本院相同。有 12 床分別有單人房及雙人房，有 50% 為先天性心臟病童，單人房主要住隔離病人。一位護理師照顧兩位病童，裝置葉克膜病童則為一對一照顧，為三班制 07:00-15:00-23:00，採電子化紀錄。在見習期間接觸 TAPVR、TGA、Glenn shunt、brain abscess 及胸骨無關之 ECMO 術後病人照顧，Q2H 翻身、晨間護理、每班確認 alarm limit、氧氣、ambu bag、插管盤及急救藥物單張。在護理照顧方面與本院現行照顧方式並無相異，翻身、晨間護理、Q8H 換 oxygenator 監測位置。因顧及病人運送安全，進行關胸骨手術亦在加護病房進行床旁手術並連絡手術房護理師協助當助手，PICU 護理師從旁協助。照顧葉克膜(Medos)需要每小時檢查管路是否有血栓產生，每四小時

APTT 須維持在 50-80 秒未進行 ACT 檢驗，此與本院相異。術後心臟病童生命監測儀器皆使用腦部血氧飽和度監測儀，以監測腦部血氧情形(monitring of cerebral oxygenation)。根據 2009 年 single medical center 針對兒童進行大規模的隨機控制研究法針對重病孩童血糖之研究結果(Intensive insulin therapy for patients in paediatric intensive care: a prospective, randomised controlled study)，目前比利時心臟病術後病童皆須監測血糖，至 PICU 依第一次 ABG 血糖值來調整 insulin infusion 輸注速度並在術後第一天內進行每小時 ABG 分析、第二天開始每四小時抽 ABG 如病童狀況穩定可以 hold 執行 ABG;小於一歲血糖控制 50-80mg/dl、大於一歲血糖理想值 70-100mg/dl，術後一星期內只給 D5W 及脂質、第八天才給予 TPN。止痛鎮靜藥物則是使用 Fentanyl、Dormicum 或 Paracetamol。對於拔管病人狀況評估是否使用 airVO2 flow 2L/kg 協助病童通氣。乳糜胸病童則使用 Lipistart®提供 high medium-chain triglycerides (MCT) 及 low long-chain triglycerides (LCT)飲食。KCL 靜脈輸注及控制血液中正常濃度範圍對於本院兒童外科加護病房的新進護理師經常感到困惑，在見習單位提供一個方便計算方式，通常心臟病童希望維持在 3.5-5mmol/L，最好狀態維持於 4.5 mmol/L。公式:上升血液中 1mmol/L=體重/2-3=所需 KCL mEq/hr/time，例如:4 公斤/2=2mEq/hr/time via cvc。



圖 34 intubation 用物(上鎖)



圖 35 雙人床景



圖 36 消毒溶液



圖 37 藥櫃 (位於護理站內)



圖 38 手術傷口感染使用 VAC 傷口



圖 39 病嬰單位



圖 40 胸腔引流瓶



圖 41 PICU 走道

三、進修心得

非常榮幸有這次機會可以到歐洲國家了解臨床實務工作如何與學校研究做連結並推廣至臨床實務操作面、護理臨床實際照護工作、落實家庭醫師制度、由下而上的政策制定及醫療院所對先天性心臟病一連串有系統計畫性的照顧。在心臟病兒童有計畫地照顧方面，一經產科醫師發現胎兒可能有心血管異常即將孕婦轉介至 fetal cardiology consultation 進行胎兒心臟超音波詳細診斷，確診胎兒有心臟病後將孕婦轉診至 fetal cardiac CNS 接受護理諮詢或了解胎兒心臟病嚴重高之後準父母可以選擇 abortions for fetal abnormality。願意產下胎兒者在妊娠最後一個月，護理師會連絡當月是預產期的準父母們參加 session，一同被帶到兒童加護病房及病房參觀，因為生產醫院和治療兒童心臟病醫院分屬不同醫院，

新生兒在一出生後會被救護車送至治療心臟病的專科醫院進行後續治療與母親分離，此 session 目的為使準父母預先了解新生兒會面臨到的手術及被治療所處的環境、手術後的外觀、產後母乳應如何保存才能讓嬰兒在可以進食時喝到母乳。住院期間學齡期病童學校老師至 hospital school 教導學業美術部分。接受手術、加護病房及病房照顧，在準備出院當天 CHD CNS 會再次家屬確認返家後照護事項，由病房護理師將病童病歷摘要等健康資訊以郵寄方式寄給家庭醫師、Community health nurse、health visitor 或學校，返家六周後再回專科醫院複診。平時由家庭醫師追蹤病童健康，回專科醫院追蹤時間間格半年至兩年不等，並由家庭醫師以 mail 方式聯絡 CHD consultation 病童目前健康狀況。專科醫院也定期派 CHD consultation 及 CHD CNS 共同至郊區兒童醫院駐診，以方便偏遠病童不用舟車勞頓學校請假至市中心。在病童 12-16 歲期間，CHD transition team CNS 介入指導病童學會照顧自己疾病，目的使其順利轉度至成人的照護模式，病情需要時並帶至成人心臟科病房參觀，亦在成人時在 adult CHD clinic 就診並接受優生保健諮詢。當中皆可見護理師的角色在預防、治療及後續追蹤扮演極重要角色。

如病童因病情而生命受限之情況下，由 PICU palliative care team 介入照顧。不只醫事成員的參與，社工與 play specialist 等大量的人員的分工細緻的配置及詳細的制度才有連續性的照顧計畫，不僅僅是急重症照顧，在教育病童自身保健及預防疾病造成的合併症在知能上更是完整落實全面性的概念。在兒童緩和

照顧部分，以 National institute for health and care excellence guideline 2016 (NICE guideline 2016)為根據，由緩和醫療小組成員每周共同討論病情、照護方向，服務對象包含住院、hospice setting 及返家照顧之 life-limiting condition 病童。相較於國內國情，急重症照護的醫療品質一直是被重視的，此次在倫敦見習時與 PICU 護理師及 palliative care team nurse (PICU senior sister)分享臺大醫院介紹、國內及本院對於先天性心臟病兒童手術後存活率及裝置葉克膜病童存活率概況介紹，討論中了解英國統計葉克膜裝置後病童存活率約莫 45%與本院目前統計狀況差異不大。但對於疾病嚴重度高，如:單一心室循環或面臨生命限制的病童接受緩和醫療照顧，如何與家屬談論兒童緩和醫療、決定 withdraw 及 withhold 的時機點對於他們也是困難決定及提出的，因此在 2017 年建立 pediatric advance care plan。對於病童的積極救治給予家屬希望並讓病童有生活品質的存活相信是大家的希望，但是面對生命受限的狀況下，如何讓家屬和病童舒服平和的渡過。這過程不只我們覺得困難，連第一個實施兒童安寧緩和的英國的 PICU 資深護理人員也覺得這是一個困難的議題，因此該院目前以問卷方式進行研究先了解臨床醫療人員（護理師、醫師）對於兒童安寧的看法、對法源的了解、接受安寧緩和在職教育等是否足夠醫療人員在真實面對緩和照顧議題時可以有自信可以勝任，並訪談 palliative care team 成員對兒童安寧的看法、共同腦力激盪目前該院可以先著手改善的方向。討論實施一連串教育訓練、帶領醫院護理師到 hospice setting 機構參觀等。英國因醫療人員分工細緻、除了醫師護理師之外，

營養師、職能治療師、遊戲治療師、兒童心理師、family liaison (Multidisciplinary team)等也每日與病家們也有密切接觸，在共同會議中可以提出自己看法，不僅僅是重症醫療照顧，更考慮到家庭的需求，給予家屬在每個決策後可能會面對的問題之心理準備及時間思考，強調 “If something happens and you are not prepared for it, then it is a disaster and a crisis. If you know what might happen, if you have got a plan for how you might manage that, if you have got a plan that will work, and if you have also got somebody that you can phone up and speak to immediately and get some advice, that can make all of the difference.” 這種細膩的全方面的思考是值得學習的。

然而，第一天進見習醫院看到環境設備是受衝擊的。在兒科病房就設有門禁，需要磁條或表明來意後才能進入，開門鈕設置在需要踮起腳尖才按得到的角落，目的是為了兒童安全，其他成人病房並無此設置。每床病床旁皆備有不同尺寸的 nasal airway、mask 及 Ambu bag;交接班時確認 alarm limit 及氧氣抽痰設備功能;每個病房皆備有急救車，且在病危狀況不穩定病童（未關胸、病危或裝置葉克膜）每日白班護理師須預抽急救藥物數支;急救訓練小組在病房（Q2W）及 PICU（QW）密集舉辦的急救訓練;體外維生系統的備機;靜脈注射針筒和管灌空針用不同廠牌顏色區別來避免途徑錯誤情況發生;每種藥物進行雙人覆核;藥物櫃上鎖，皆都顯示有預防觀點，讓發生緊急狀況時，能夠從容處理將傷害降至最低。與國內有差異部分在執行醫療照顧過程中，醫療人員並不需要戴口罩

髮帽，但需要穿圍裙及戴手套、只有正在進行床旁手術或照顧隔離病人時才需配戴口罩或髮帽;在 PICU 家屬被允許 24 小時陪伴但夜間只能留一位家屬、在床邊可以被允許喝有杯蓋的茶或咖啡、小餅乾，bedside 護理師亦然。

在見習過程中，在英國 Royal Brompton Hospital 的會議中分享了本院臨床兒科及兒童加護病房目前現況，與會護理師皆表示對臺灣護病比例感到無法想像，在整體照護心臟病童之存活率及葉克膜裝置病童存活率卻與英國差異不大感到驚奇。反思這幾個國家醫院照護上的差異，英國醫院因為醫事人員眾多照顧病人數少但醫院設備卻不新穎，因此，包括每個病房內至少都要有一位護理師在病房內監測個病童的情況，單位因為病童、家屬及醫事人員多以致環境吵雜;各類醫事人員多等待溝通有共識需要花更多時間。病人隱私部分，病房內有公開大螢幕顯示每床病童姓名、疾病及照顧護理師及醫師，與國內實施差異甚大。比利時醫院 PICU 成員配置及護理師照護人數與院內現行制度類似。臺灣醫療人力不似國外的充裕，我們臨床護理人員常常包攬很多超乎護理領域之外的職責和溝通，似乎可以培養成一個廣泛了解的人員，但可能因為年資和累積經驗不同，對於臨床照護以外的資訊獲得並不一致，因此對與給予病童和家屬的資訊也可能有異。光依臺灣現行制度及護病比而言，臺灣急重症護理品質、積極治療方面，身為急重症護理人員的我認為是可以非常驕傲的。但如果可以更廣泛的看待健康照護這件事，有對「人」個體有更完整、延續性和柔軟的思考，不僅只著重於眼前疾病積極治療，進一步考慮整個家庭或病童的後續生活品質，

由進階護理師灌輸慢性病青少年開始學習有自我照顧的概念，用公衛預防的觀點避免慢性病青少年長至成年期因不良生活型態造成併發症的發生或，或許可以降低國家健康保險的支出。

四、建議事項

此次進修經驗並依據臺灣目前國內的醫療體制，提出下列建議以供實際兒童醫療照護之參考:

(一) 先天性心臟病童照護方面

在參訪上述各家醫院兒童單位，發現在醫材方面皆用單次拋棄式醫材，包含體溫表;完整皮膚消毒及手術傷口換藥方面，針對不同尺寸傷口備有 wound care pack、suture remove pack (stitch cutter、laminated sheet、forceps、non-woven swabs、dressing towel 及 disposal bag)、chloraprep with tint，雖然醫療廢棄物增加，但可以減少備物等交互感染之問題。執行侵入性治療時可視情況提供嬰兒少許糖水以安撫哭泣情況，如:驗血糖、拔管路或放置周邊靜脈血液導管;在放置周邊靜脈導管時可使用 local anesthetic spray 或 Emla cream 減少病童執行穿刺之疼痛感。心臟病嬰因住院長期放置氣管內管或因吸吮費力需要放置鼻胃管，新手父母碰到小孩身上有管路還要返家照顧總會感到焦慮不安，如果需要可以建議家屬購買簡易型 PH 試紙，在灌食前反抽鼻胃管並用試紙檢測確定管路是否在胃部，確保灌食安全。在政策執行實施「Self-administration of medication」是讓我最感到驚艷，目的並不是降低護理師給藥的負擔，而是依據照顧者能力進行給藥

能力評估，藉由此制度讓病患家屬可以參與學習自我健康照顧的重要環節為自我健康負責，建議此項政策可依據本土國民特性設計適當的配套措施進而提供可以完善實施於臨床制度。因兒科病房照護人數多，除病房常規測量病童生命徵象之外，對於病童住病房期間病情漸差，護理師多久探視一次並無可遵循之依據，在護理教育及臨床照顧方面，將 Bedside pediatric early warning system 引用於兒科教育及考慮鍵入目前 portal 電腦系統以得分方式提醒醫護人員，提早偵測到病童病情惡化。

（二）兒童緩和醫療議題

兒童安寧緩和醫療議題在見習時接觸的兒科緩和醫療護理師討論皆認為這是困難開口的過程，在 Royal Brompton Hospital 醫院裡從 2017 年到見習期間使用 Advanced Care Plan 使用過兩次，期望將此表單翻譯修改成適合本土生命末期兒童的照護需求計畫。但藉由此次進修了解那些先天性心臟病是需要緩和醫療介入，在臨床實務方面針對單一心室病童可以將 Little Hearts Matter 翻譯之疾病治療手冊讓家屬可以知道將面臨哪些階段和會面臨的狀況，提早做心理準備。兒童緩和安寧在國內推行充滿困難挑戰，此議題在所有的兒科相關醫療人員也不盡了解，常與不施予急救同意混淆，對於兒童緩和醫療教育需要再提升，經過醫事人員會議討論，辨識病童病情提早介紹兒童緩和安寧服務，讓家屬知道有那些選擇可以讓孩童有更好的生活品質，但這些需要醫療團隊合作下才能有共識推行。病童在生命受威脅或臨終之前提早轉介給院內安寧共照小組中負責

兒童安寧護理師，讓後續照護方向及家屬哀傷支持可提早做準備，也可進一步透過研究瞭解國內經急重症照護後喪子的家屬需要那些實際支持是目前緊縮人力的醫療院所可以提供的服務。

五、致謝

此次進修非常感謝臺大醫院提供這次難得的機會，能讓自己在每天繁忙的重症加護病房工作之外，能到英國及比利時學習先天性心臟病從 fetal 到 adult 連續性實務照護及研究議題的探討。在得知准許出國並著手準備的五個月期間因時間因素及與對方醫院、學校教授聯繫流程、文件之準備備感壓力。非常感謝護理部長官的支持與打氣，尤其感謝黃月嬌副主任、余春娣督導長、吳靜宜督導長、范圭玲督導長、曾紀瑩督導長及吳美華護理長讓我可以全心準備，李馨芬護理長在我剛獲知消息毫無頭緒向她求援時，給予打氣及熱情分享出國準備資料的優先次序、高碧霞副教授的鼓勵和支持、陳紀雯教授的打氣和協助聯繫國外教授、Royal Brompton Hospital 的 senior nurse Liz Biggart、Lucy Foster、Neil West 規劃三個月見習行程及住宿、魯汶大學 Philip Moons 教授像爸爸也像朋友的溫暖指導，促使這次出國進修的目標及過程才能如此順利達成。從去年八月開始準備到完成進修計畫的期間不確定是否會因自己疏失而無法順利成行，感謝多人溫暖熱心的幫忙。



to improve the outcomes of hospitalized children

Using the Bedside PEWS documentation record

1 Measure vital signs on your patient

in the scenarios these will be given to you
at the bedside a complete assessment includes the 7 vital signs

2 Document on the Bedside PEWS documentation record

graph on the lines
write in the boxes
sum the sub-scores from the 7 indicators
round up measurements that are 'on-the-line'

3 Interpret

vital signs and their sub-scores are objective information from the patient
interpret the score
it helps objectively describe how sick your patient is
absolute severity
temporal change

4 Review Your Responses to your patients current condition

Bedside PEWS Score Matched Care Recommendations describe Levels of Care
Frequency of vital sign documentation
Senior / charge Nurse Review
Physician Review
ICU review
ECG & saturation monitoring
Nurse: Patient Ratio

the Bedside PEWS is a documentation-based system of care

implementation of Bedside PEWS involves change
changing how we provide care to children in hospital
the change involves you
it involves all frontline clinicians,
all their clinical supervisors
and all hospital administrators

the purpose of Bedside PEWS is to help you & your colleagues

identifying children at risk, enabling intervention, preventing deterioration

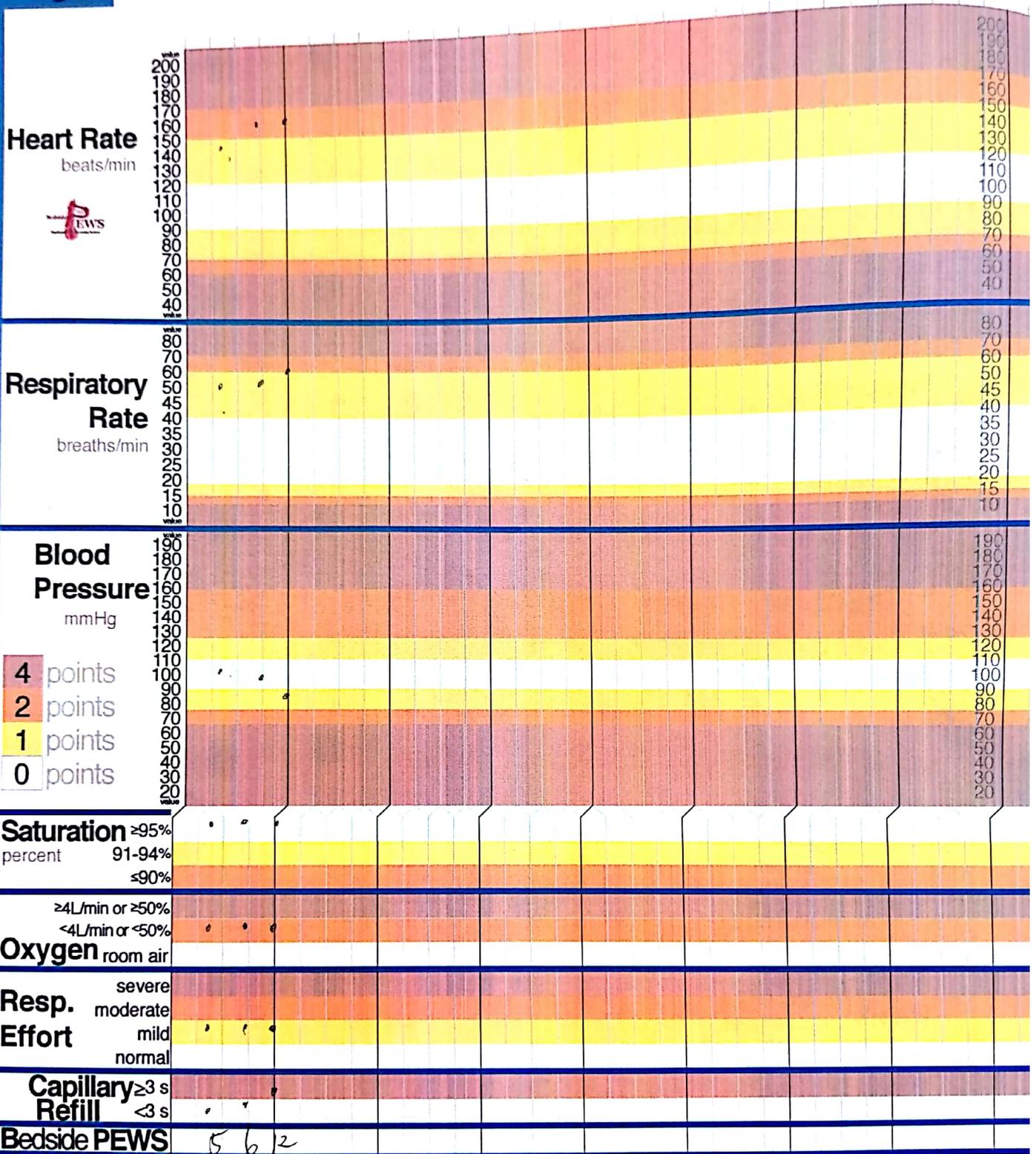
improve the outcomes of hospitalized children

educational scenarios for scoring practice



1-5yr

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for educator use

recalculation _____

age _____

feedback _____



≥12yr

educational scenarios for scoring practice



Heart Rate beats/min 	190										190
	180										180
	170										170
	160										160
	150										150
	140										140
	130										130
	120										120
	110										110
	100										100
90										90	
80										80	
70										70	
60										60	
50										50	
40										40	
30										30	
Respiratory Rate breaths/min	60										60
	55										55
	50										50
	45										45
	40										40
	35										35
	30										30
	25										25
	20										20
	15										15
10										10	
5										5	
Blood Pressure mmHg 4 points 2 points 1 points 0 points	200										200
	190										190
	180										180
	170										170
	160										160
	150										150
	140										140
	130										130
	120										120
	110										110
100										100	
90										90	
80										80	
70										70	
60										60	
50										50	
40										40	
30										30	
Saturation percent	≥95%										
	91-94%										
	≤90%										
Oxygen room air	≥4L/min or ≥50%										
	<4L/min or <50%										
Resp. Effort	severe										
	moderate										
	mild										
	normal										
Capillary Refill	≥3 s										
	<3 s										
Bedside PEWS											

for educator use	
recalculation	
age	
feedback	





**PAEDIATRIC PRESSURE ULCER RISK EVALUATION TOOL
& ACTION PLAN**

LEVEL OF CONSCIOUSNESS	1. Aware	2. Voice Responsive	3. Pain Responsive	4. Unresponsive
MOBILITY	1. Fully Mobile	2. Limited : needs help to move	3. Bed Bound or Wheelchair Bound	4. Paralysed or Neuro Disability
√ WEIGHT	1. Normal for Age	2. Premature Baby	3. Overweight	4. Failure to Thrive (Faltering Growth)
NUTRITION	1. Normal Diet for Child	2. Nil by Mouth	3. Malnutrition	4. TPN
√ SKIN	1. Intact	2. Sensitive : Rash or Eczema	3. Wet : Incontinent, Diarrhoea or Exudate	4. Easily Marked, Broken or Oedematous
√ CAPILLARY REFILL	1. <2 Seconds	2. 2-3 Seconds	3. 3-5 Seconds	4. >5 Seconds
√ OXYGEN SATURATIONS	1. >93%	2. 85-92%	3. 75-84%	4. <75%
√ SURGERY	1. <3 Hours	2. 3-6 Hours	3. >6 Hours	4. Chest Stented
√ MEDICATION	1. No Sedation or Inotropes	2. Sedation	3. Sedation and/or 1 inotrope	4. Sedation and/or 2 Inotropes
√ SPECIAL RISKS	1. None	2. Unstable Blood Glucose and/or NGT/NJT	3. Respiratory Support	4. ECMO, HFOV, SiPAP, NIV or CVVH

VJH April 2017

Appendix 2: Parent/Carer Information Self-administration of medication

What is self-administration?

It is a system where you, the parent/carer are given responsibility for giving medicines on the ward, just as you do or will do at home.

What are the benefits?

- It is an opportunity for you improve your knowledge of the medicines you are giving
- It enable you to maintain your independence
- It helps the ward team identify any problems you might be having with your child's medicines
- It helps you learn how to best give the medicines when you go home

Do I have to take part?

No. Self-administration is not compulsory. If you wish the nurses can administer your child's medicines on the ward. Information on your child's medicine will still be provided during your stay.

How will it work?

1. Assessment

The nurse or pharmacist will first assess your ability to give the medicines. This will highlight any problems you may have, for example ability to read labels or difficulty opening containers.

Before starting, the nurse or member of the ward pharmacy team will explain;

- What self-administration of medicines is about
- What medicines your child is taking and why they are taking them
- The dose and how and when to give the medicine
- Any side-effects that you should know about

There are different levels of self-administration:

Level 1: The nurse will give you your child's medicines from your locker and observe you giving them. Please note nurses will intervene if they see any mistakes being made.

Level 2: The nurse will inform you that it is time to give the medicines and you will be responsible for giving them. However the nurses will observe the administration and intervene if required.

Level 3: You are given full responsibility for administering your child's medicines and for signing that you have done so on the in-patient medicine chart.

The multidisciplinary team, nurse and you will decide on the level that is right for you. The level of administration may change during your child's stay.

If you wish to self-administer the nurse will then ask you to sign a consent form.

2. Preparation

Please ensure that you bring in sufficient supplies of ALL medicines that you give at home.

All information will be supplied on admission, however if you would like to know more or have any questions prior to your stay please contact your CF Clinical Nurse Specialist.

Supplies of medicines

The medicines (the ones you brought into hospital) will be used if suitable. This will allow you to use medicines that you are already familiar with and also avoid waste.

Children are more likely to take the medicines they are used to (and if they don't please discuss with the pharmacy team who will be able to assess and offer advice on how to help them).

If you have not brought in all the medicines with you or the ones you have brought are not suitable for use e.g. the expiry date is not clear, or if you have been started on a new treatment, then pharmacy will provide you with a supply from the hospital pharmacy labelled with your child's name and with directions on how to give it.

Please note that only **NEW** medications will be issued on discharge, and that all regular medications should be obtained through your usual methods.

Medicines that you won't be asked to self-administer

Usually only medicines that can be stored in the POD locker (this is the bedside medicine cabinet, POD stands for Patient's Own Drugs) will be suitable for self-administration.

Some medicines will not be suitable for you to self-administer. This list will be dependent on the level of administration and may include;

- Medicines that need to be stored in the refrigerator,
- Medicines that need to be kept in locked cupboard on the ward, these include 'Controlled Drugs' such as morphine preparations for example *MST*[®] tablets. Controlled Drugs including any you bring to hospital-will be kept in the ward's Controlled Drugs cupboard. Controlled Drugs cannot be stored in the POD locker,
- Medicines administered intravenously,
- Medicines supplied in multi-dose compliance devices such as *Dosset*[®] boxes. If you need to use these devices you may not be asked to self-administer.
- If you do wish to self-administer then pharmacy will supply all the items in the compliance device in individual boxes or in the Pharmacy's own compliance device. If your compliance device includes Controlled Drugs, and you wish to continue using this type of device in hospital, then pharmacy will dispense all items except the Controlled Drugs in the device. The Controlled Drugs will be issued from the supply stored in the Controlled Drugs cupboard.

3. Storage of medicines

Please keep all medicines locked away in the POD locker. Each POD locker is fitted with an electronic digital lock. This will be programmed to a number combination of your choice at the beginning of your stay, and changed when you leave. Care must be taken that this locker combination is not revealed to others.

4. Information on medicines

In order to understand your child's medicines better, you may be given a medicine's information card showing names of the tablets and the correct dose, and instructions on how to give them.

Patient information leaflets are also supplied with the medicine containers. Hospital staff will have access to your medication cabinet; therefore please do not store any valuables in with the medication.

5. DO's and DON'Ts

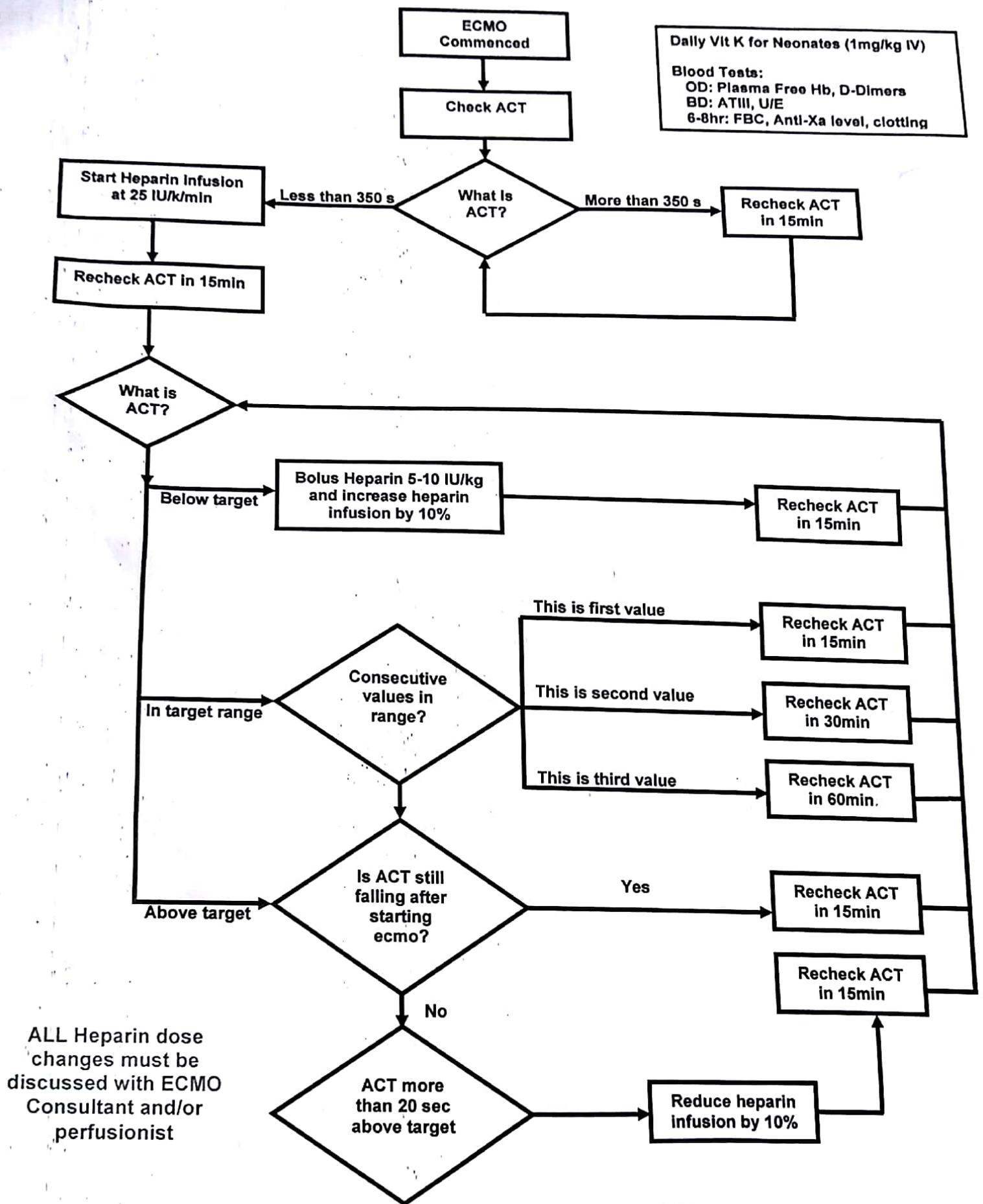
- If the child you care for experiences any side effects do not stop giving the medicines but inform your doctor, nurse or pharmacist **IMMEDIATELY**.
- Keep all medicines out of the reach of other children; therefore it is important the medicine locker is locked at all times whilst not in use.
- It is **YOUR** responsibility to keep the medicines in a safe place.
- If a visitor or other patient tries to take your child's medicines, inform a nurse immediately.
- Never share medicines with anyone else.
- If you forget to give a dose of medication, tell a member of the nursing staff.
- Do not exceed the prescribed dose.
- Do not give any medicines that have not been prescribed on the in-patient chart. If you usually give medicines that haven't been prescribed then inform the doctor, nurse or pharmacist **IMMEDIATELY**.
- If you are running low or have run out of supplies tell a member of the ward pharmacy team or a nurse.
- If you are unable or feel unable, at any time, to administer medicines inform the nurse **IMMEDIATELY**.

Heparin management algorithm for children on ECMO

(Any deviation from pathway must be discussed with ECMO consultant and documented)

Daily Vit K for Neonates (1mg/kg IV)

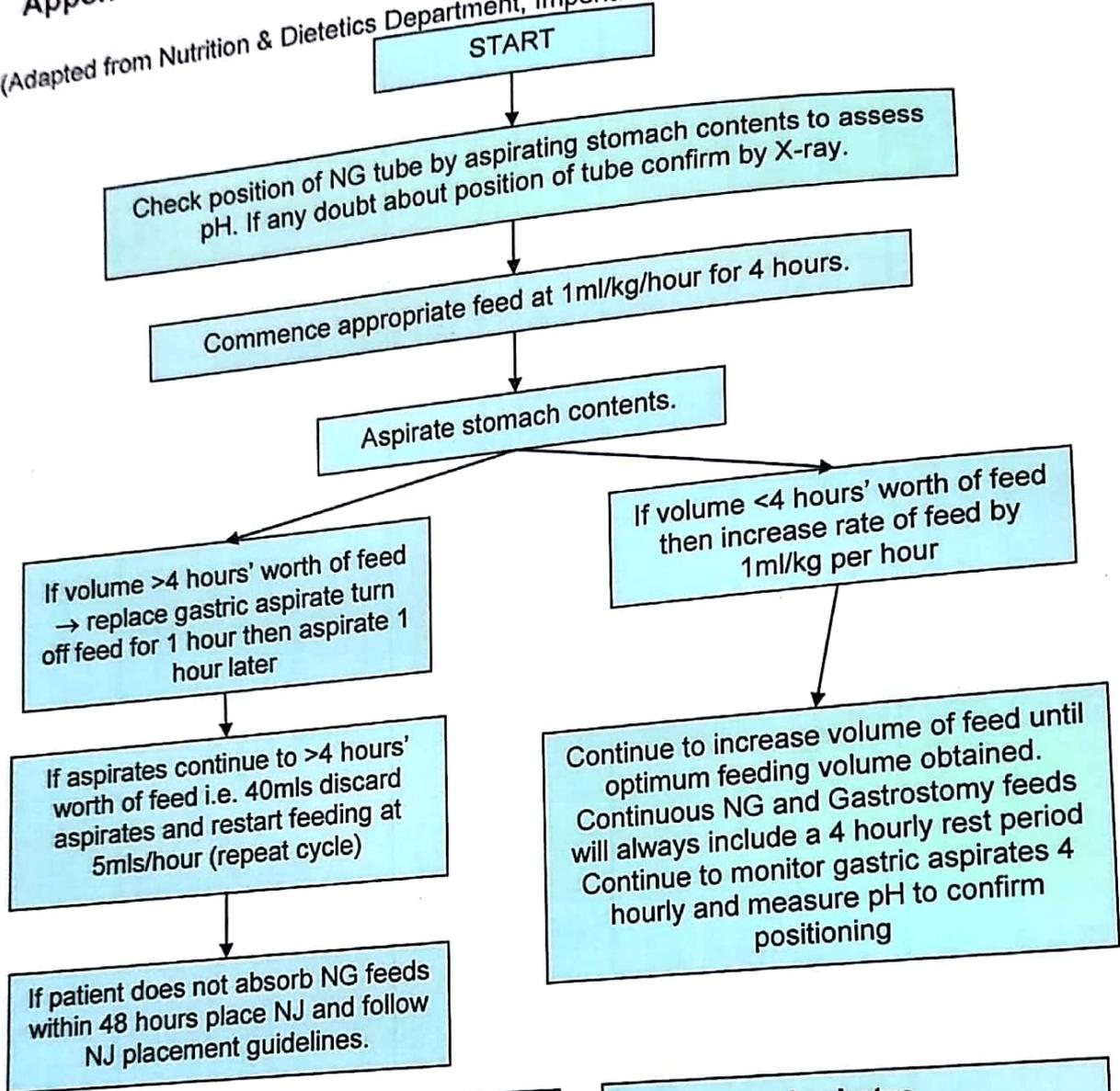
Blood Tests:
 OD: Plasma Free Hb, D-Dimers
 BD: ATIII, U/E
 6-8hr: FBC, Anti-Xa level, clotting



ALL Heparin dose changes must be discussed with ECMO Consultant and/or perfusionist

Appendix 7.5: Gastric Feeding Challenge Algorithm on PICU (<12 months & <10kg)

(Adapted from Nutrition & Dietetics Department, Imperial College Healthcare).



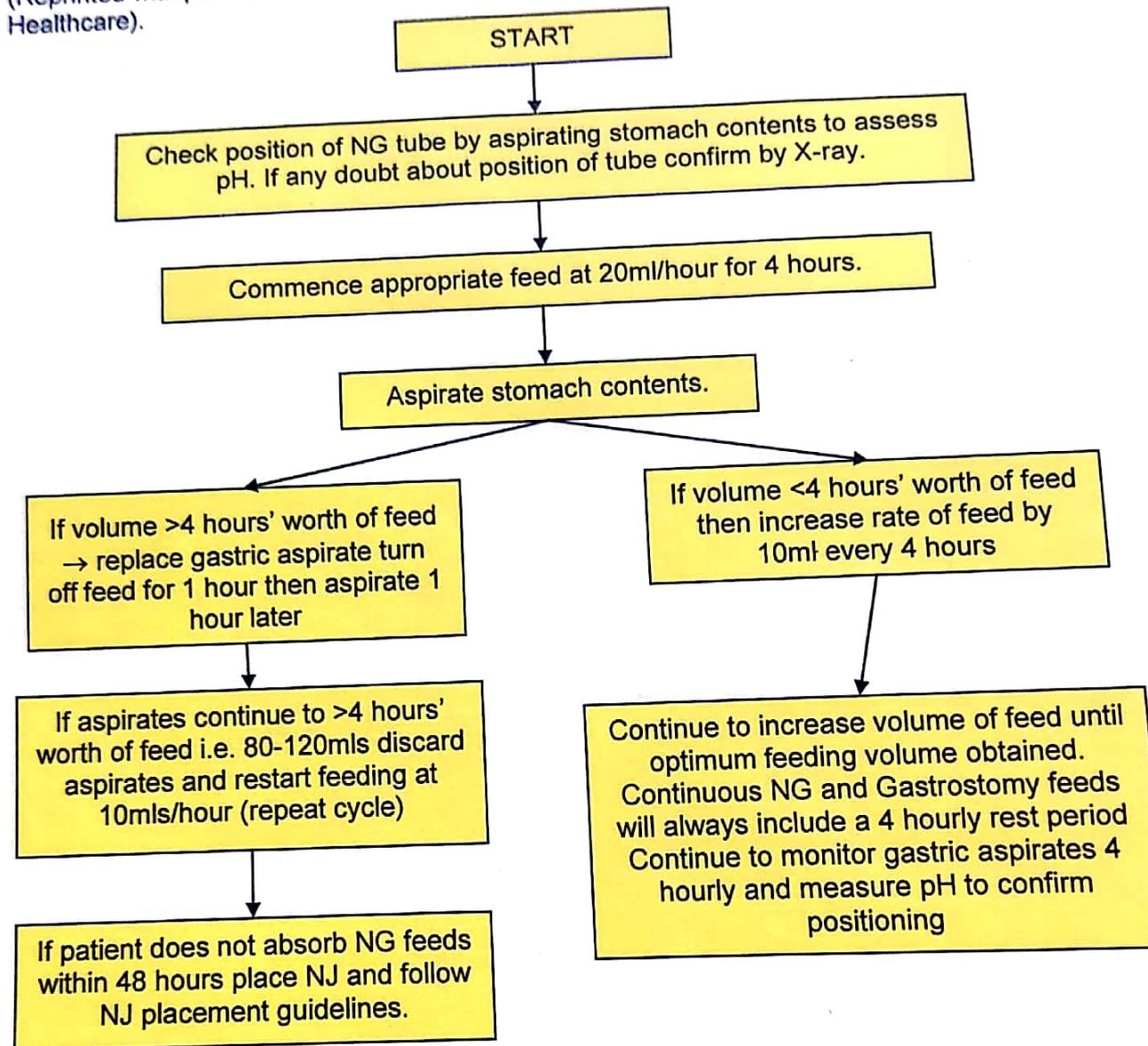
- Suitable feeds**
- EBM (+/- fortification)
 - Standard infant formula (SMA Gold / Cow & Gate 1st)
 - Preterm infant formula (Nutriprem 1)
 - Infatrini (high energy formula)
 - Neocate LCP (allergy, intractable malabsorption)
 - SMA LF (lactose free formula)
 - Peptijunior (semi-elemental - malabsorption)
 - Nutramigen (diarrhoea and milk intolerance).

Aspirates

If aspirates are largely bile, blood, and undigested feed or if patient vomits, then discontinue gastric feeds and restart after 1-hour rest.

Appendix 7.2: Gastric Feeding Challenge Algorithm on PICU (>10 years & >30kg)

(Reprinted with permission from Nutrition & Dietetics Department, Imperial College Healthcare).



Suitable feeds

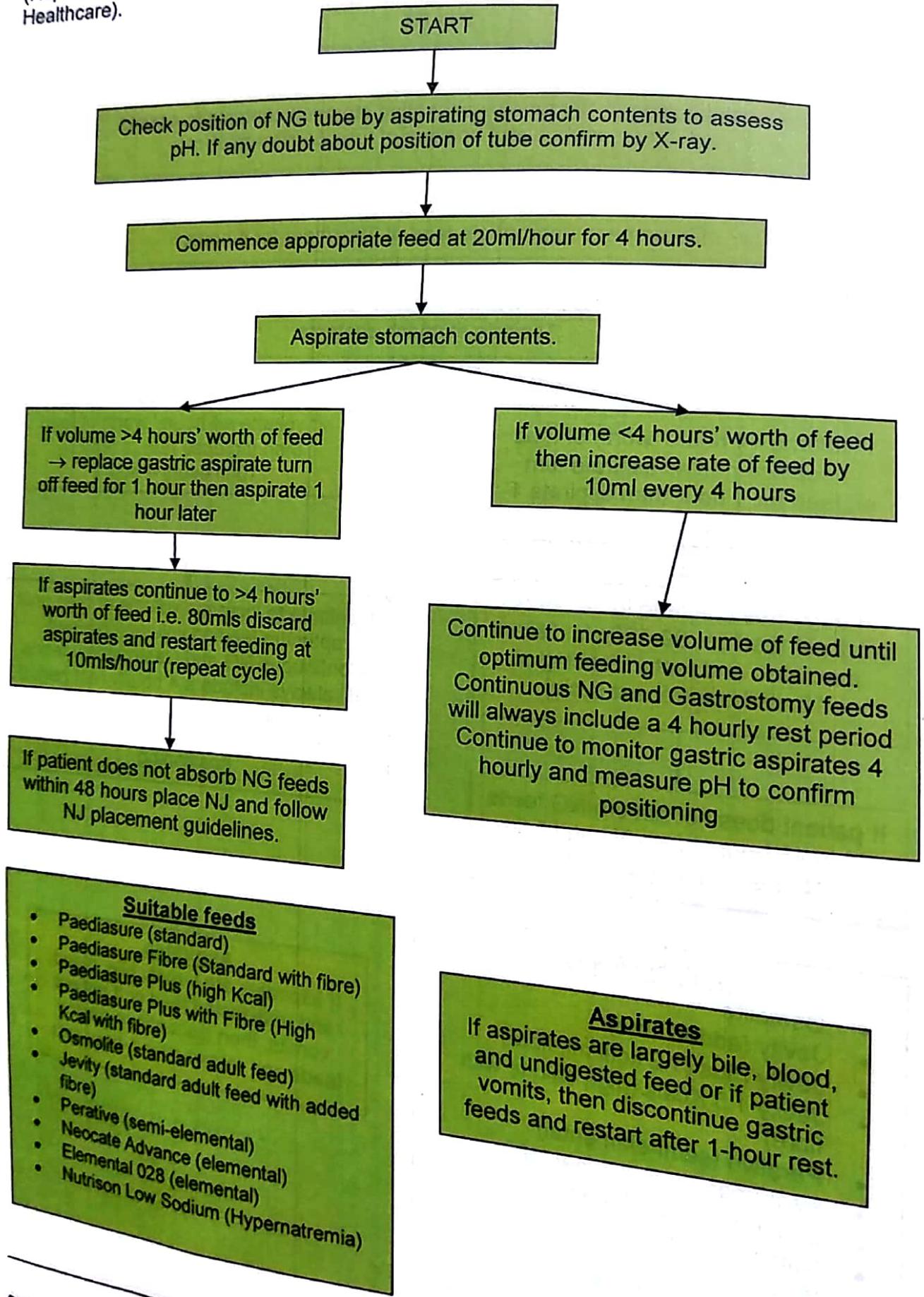
- Osmolite
- Jevity (added fibre)
- Jevity Plus (1.2 kcal/ml, fibre)
- Jevity 1.5 Kcals (high calorie with fibre)
- Perative (semi-elemental)
- Peptamen (semi-elemental)
- Elemental 028 (elemental)
- Nutrison Low Sodium (hyponatraemia)
- Nepro (low electrolyte)

Aspirates

If aspirates are largely bile, blood, and undigested feed or if patient vomits, then discontinue gastric feeds and restart after 1-hour rest.

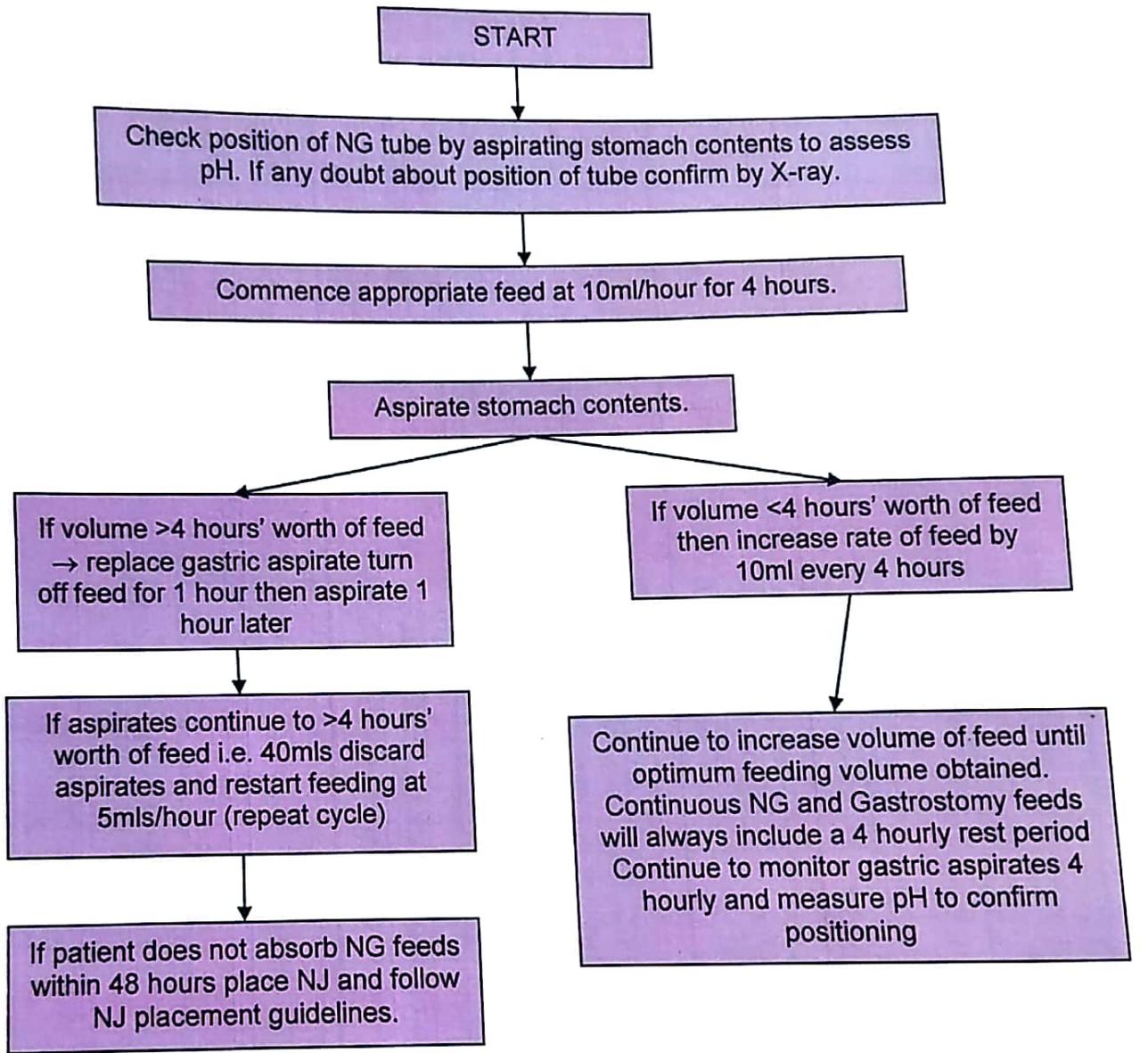
Appendix 7.3: Gastric Feeding Challenge Algorithm on PICU (6-10 years & 20-30kg)

(Reprinted with permission from Nutrition & Dietetics Department, Imperial College Healthcare).



Appendix 7.4: Gastric Feeding Challenge Algorithm on PICU (1-6 years & 10-20kg)

(Reprinted with permission from Nutrition & Dietetics Department, Imperial College Healthcare).



- Suitable feeds**
- Paediasure (standard)
 - Paediasure Fibre (standard with fibre)
 - Paediasure peptide-malabsorption
 - Paediasure Plus (high Kcal)
 - Paediasure Plus Fibre (high Kcal with fibre)
 - Peptijunior (< 2 years diarrhoea, malabsorption)
 - Neocate Advance (Elemental).

Aspirates

If aspirates are largely bile, blood, and undigested feed or if patient vomits, then discontinue gastric feeds and restart after 1-hour rest.

Congenital Heart Disease Transition Pathway

Preferred name:		
Gender:	Male / Female	
Address:	(Circle preferred contact number) Home Tel: Mobile Tel: Email address: Consent for email contact: Yes / No	
Preferred Language:	Interpreter required: Yes / No	
Disabilities: Learning disability Hearing loss Physical disability Mobility aids required	No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/>
Consent to share information with next of kin unless otherwise stated: Yes / No		
Next of Kin name:	Relationship:	
Address: Same as patient	Same as patient Home Tel: Mobile Tel: Email address: Consent for email contact Yes / No	
Preferred language:	Interpreter required: Yes / No	

Specialist Cardiac Centre Contacts

Designation	Name	Contact Details
Lead Paediatric Cardiology Consultant		
Lead Transition Clinical Nurse Specialist		
Lead ACHD Transition Consultant		
Lead ACHD Clinical Nurse Specialist		

Local Specialist and Community Team Contacts

Designation	Name	Contact Details

Signature Log

Name	Designation	Signature	Initials	Date

Baseline Assessment

Patient Age:

Date:

HR _____bpm

Weight _____kg

Height_____m

BP _____/_____

O2 sat (air) _____%

BMI _____

Follow-up Assessment

Patient Age:

Date:

HR _____bpm

Weight _____kg

Height _____m

BP _____/_____

O2 sat (air) _____%

BMI _____

Follow-up Assessment

Patient Age:

Date:

HR _____bpm

Weight _____kg

Height_____m

BP _____/_____

O2 sat (air) _____%

BMI _____

Follow-up Assessment

Patient Age:

Date:

HR _____bpm

Weight _____kg

Height _____m

BP _____/_____

O2 sat (air) _____%

BMI _____

Name:

BMI Chart

height (m)	height (m)																weight (kg)	weight (st./lbs)
	1.38	1.42	1.46	1.50	1.54	1.58	1.62	1.66	1.70	1.74	1.78	1.82	1.86	1.90	1.94	1.98		
150	79	74	70	67	63	60	57	54	52	50	47	45	43	41	39	38	23s 8	
148	78	73	69	66	62	59	56	54	51	49	47	45	43	41	39	38	23s 3	
146	77	72	68	65	62	58	56	53	51	48	46	44	42	40	39	37	22s 13	
144	76	71	68	64	61	58	55	52	50	48	45	43	42	40	38	36	22s 9	
142	75	70	67	63	60	57	54	52	49	47	45	43	41	39	38	36	22s 4	
140	74	69	66	62	59	56	53	51	48	46	44	42	40	39	37	35	21s 10	
138	72	68	65	61	58	55	53	50	48	46	44	42	40	38	36	35	21s 5	
136	71	67	64	60	57	54	52	49	47	45	43	41	39	38	36	34	21s 1	
134	70	66	63	60	57	54	51	49	46	44	42	40	39	37	36	34	20s 10	
132	69	65	62	59	56	53	50	48	46	44	42	40	38	37	35	33	20s 6	
130	68	64	61	58	55	52	50	47	45	43	41	39	38	36	35	33	20s 2	
128	67	63	60	57	54	51	49	46	44	42	40	39	37	35	34	32	19s 12	
126	66	62	59	56	53	50	48	46	44	42	40	38	36	35	33	32	19s 7	
124	65	61	58	55	52	50	47	45	43	41	39	37	36	34	33	32	19s 3	
122	64	61	57	54	51	49	46	44	42	40	39	37	35	34	32	31	18s 13	
120	63	60	56	53	51	48	46	44	42	40	38	36	35	33	31	30	18s 8	
118	62	59	55	52	50	47	45	43	41	39	37	36	34	33	31	30	18s 4	
116	61	58	54	52	49	46	44	42	40	38	37	35	34	32	31	30	17s 13	
114	60	57	53	51	48	46	43	41	39	38	36	34	33	32	31	30	17s 9	
112	59	56	53	50	47	45	43	41	39	37	35	34	32	31	30	29	17s 5	
110	58	55	52	49	46	44	42	40	38	36	35	33	32	30	29	28	17s	
108	57	54	51	48	45	43	41	39	37	36	34	33	31	30	29	28	16s 10	
106	56	53	50	47	45	42	40	38	37	35	33	32	31	29	28	27	16s 5	
104	55	52	49	46	44	42	40	38	36	34	33	31	30	29	28	27	16s 1	
102	54	51	48	45	43	41	39	37	35	34	32	31	29	28	27	26	15s 10	
100	53	50	47	44	42	40	38	36	35	33	32	30	29	28	27	26	15s 6	
98	51	49	46	44	41	39	37	36	34	32	31	30	28	27	26	25	15s 2	
96	50	48	45	43	40	38	37	35	33	32	30	29	28	27	26	24	14s 11	
94	49	47	44	42	40	38	36	34	33	31	30	28	27	26	25	24	14s 7	
92	48	46	43	41	39	37	35	33	32	30	29	28	27	25	24	23	14s 2	
90	47	45	42	40	38	36	34	33	31	30	28	27	26	25	24	23	13s 12	
88	46	44	41	39	37	35	34	32	30	29	28	27	26	25	24	23	13s 8	
86	45	43	40	38	36	34	33	31	30	28	27	26	25	24	23	22	13s 3	
84	44	42	39	37	35	34	32	30	29	28	27	26	25	24	23	22	12s 13	
82	43	41	38	36	34	33	31	30	28	27	26	25	24	23	22	21	12s 8	
80	42	40	38	36	34	32	30	29	28	26	25	24	23	22	21	20	12s 4	
78	41	39	37	35	33	31	30	28	27	26	25	24	23	22	21	20	11s 10	
76	40	38	36	34	32	30	29	28	26	25	24	23	22	21	20	19	11s 6	
74	39	37	35	33	31	30	28	27	26	24	23	22	21	20	19	18	11s 2	
72	38	36	34	32	30	29	27	26	25	24	23	22	21	20	19	18	10s 10	
70	37	35	33	31	30	28	27	25	24	23	22	21	20	19	18	17	10s 6	
68	36	34	32	30	29	27	26	25	24	22	21	20	19	18	17	16	10s 2	
66	35	33	31	29	28	26	25	24	23	22	21	20	19	18	17	16	9s 11	
64	34	32	30	28	27	26	24	23	22	21	20	19	18	17	16	15	9s 7	
62	33	31	29	28	26	25	24	22	21	20	19	18	17	16	15	14	9s 3	
60	32	30	28	27	25	24	23	22	21	20	19	18	17	16	15	14	8s 11	
58	30	29	27	26	24	23	22	21	20	19	18	17	16	15	14	13	8s 7	
56	29	28	26	25	24	22	21	20	19	18	17	16	15	14	13	12	8s 3	
54	28	27	25	24	23	22	21	20	19	17	16	15	14	13	12	11	7s 12	
52	27	26	24	23	22	21	20	19	18	17	16	15	14	13	12	11	7s 8	
50	26	25	23	22	21	20	19	18	17	16	15	14	13	12	11	10	7s 4	
48	25	24	23	21	20	19	18	17	16	15	14	13	12	11	10	9	6s 11	
46	24	23	22	20	19	18	17	16	15	14	13	12	11	10	9	8	6s 7	
44	23	22	21	20	19	18	17	16	15	14	13	12	11	10	9	8	6s 3	
42	22	21	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6s 11	
40	21	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6	6s 7	
38	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6	5	6s 3	
36	19	18	17	16	15	14	13	12	11	10	9	8	7	6	5	4	6s 11	
	4'6"	4'8"	4'9"	4'11"	5'0"	5'2"	5'4"	5'5"	5'7"	5'8"	5'10"	5'11"	6'1"	6'3"	6'4"	6'6"		

Name:

Hospital RBH&HH

DOB:

Transition Care Plan

ID	Activity	Activity Started	Activity Completed
A1	Discuss transition process with young person & family		
A2	Discuss difference between paediatric and adult services		
A3	Discuss importance of long-term specialist congenital heart disease follow-up care		
A4	Explain all available adult congenital cardiology care options		
A5	Discuss plans for long-term follow-up		
A6	Describe their heart condition using pictures and models		
A7	Ensure knowledge of any medications and discuss concordance		
A8	Discuss peer group / social issues		
A9	Discuss psychological impact of living with congenital heart disease		
A10	Inform of useful support groups and websites		
A11	Offer young person some or all of consultation without carer present		
A12	Explain confidentiality to young person and family		
A13	Explain young person's right to consent		
A14	Discuss lifestyle issues such as diet, smoking, alcohol and drugs		
A15	Discuss potential impact of exercise on their heart condition		
A16	Ensure awareness of endocarditis signs and symptoms – give advice re. tattoos, piercings and dental hygiene		
A17	Discuss adolescent development / puberty		
A18	Provide appropriate information on contraception and pregnancy		
A19	Inform of potential familial links with congenital heart disease		
A20	Discuss education plans and future employment – inform of any restrictions		
A21	Ensure knowledge of next transition follow-up appointment		

*** If patient has learning disabilities and is unable to complete checklist then checklist should be completed with carer and box ticked**

Name:

Transition Consultation Log

Date

Cardiac Condition:

.....
.....
.....
.....

Procedures:

.....
.....
.....
.....

Cormobidities (and responsible clinicians):

.....
.....
.....
.....

Medications:

Medications taken as prescribed	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input type="checkbox"/>
Involved in medicine management:	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A	<input type="checkbox"/>
Able to swallow tablets:	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Advise annual flu jab:	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		

Allergies:

Current medications:

.....
.....
.....
.....

Understanding:

Understanding of condition:	Excellent	<input type="checkbox"/>	Good	<input type="checkbox"/>	Moderate	<input type="checkbox"/>	Poor	<input type="checkbox"/>
Able to name cardiac condition:			Fully	<input type="checkbox"/>	Partially	<input type="checkbox"/>	Unable	<input type="checkbox"/>
Able to describe condition			Fully	<input type="checkbox"/>	Partially	<input type="checkbox"/>	Unable	<input type="checkbox"/>

Procedures/surgeries explained	<input type="checkbox"/>	Long term outcomes discussed	<input type="checkbox"/>
Adult F/U: Specialist ACHD team	<input type="checkbox"/>	Local specialist cardiologist	<input type="checkbox"/>

Knows who to contact if worried about symptoms

Knows which symptoms should prompt urgent review

Endocarditis:

Explained what endocarditis is	<input type="checkbox"/>	Risks	<input type="checkbox"/>
Discussed: Symptoms	<input type="checkbox"/>	Prevention	<input type="checkbox"/>
		Treatment	<input type="checkbox"/>

Understands need for regular dental visits and good oral hygiene Yes No

Prophylactic antibiotics required for dental procedures: Yes No

Name:

Hospital RBH&HH

DOB:

Date

Transition Consultation Log

Sign

Education, Employment & Travel:

Current education or employment status:

.....

Statement of educational need: Yes No

Future education or career plans:

.....

Career options and any restrictions discussed Yes No N/A

Travel insurance / EHIC discussed: Yes No

Lifestyle Issues:

Discussed importance of healthy diet and lifestyle: Yes No

Exercise recommendations given: Yes No

Symptomatic on exercise: Yes No N/A

Symptoms explained by cardiac condition Yes No N/A

Exercise restrictions discussed if any: Yes No N/A

.....

.....

Risks of recreational drugs, smoking and alcohol discussed Yes No

Discussed safe and responsible alcohol consumption: Yes No

Lifestyle leaflet given: Yes No

.....

Reproductive Health:

Discussed menstrual cycles: Yes No N/A

General reproductive health promotion advice (*circle if discussed*):
STIs, HPV vaccine, breast/cervical/testicular cancer awareness, FGM

Any specific advice given:

.....

.....

Leaflet given on contraception: Yes No N/A

Leaflet given on pregnancy: Yes No N/A

Aware of where to seek further information: Yes No

Recurrent risk of congenital heart disease in offspring: Yes Consanguinity

Informed of cardiac foetal screening: Yes No

Psychological & Social Health:

Who lives at home:.....

.....

Any family history of congenital heart disease: Yes No Unsure

.....

.....

Any family history of acquired heart disease: Yes No Unsure

.....

.....



A lifetime of specialist care

ALLERGIES
Enter details here

Name	Patient's name	DOB:
Address	Address Line1	
	Address Line2	
	Address Line3	Post code:
Hospital No.	NHS No.	Date: {dd/mm/yyyy}



Child and Young Person's Advance Care Plan Collaborative



Collaborators: Alder Hey Children's Hospital, Dorset County Hospital, Gloucestershire Hospitals NHS Foundation Trust, Helen & Douglas House Hospices, Kent & Medway C&YP Palliative Care Network, Naomi House & Jacksplace, North Hampshire NHS Trust, North West Children's Palliative Care Network, Oxford University Hospitals NHS Trust, Poole Hospital, Portsmouth Hospitals NHS Trust, Royal Berkshire NHS Foundation Trust, Royal Manchester Children's Hospital, Solent NHS Trust, Southampton Children's Hospital, St Mary's Hospital Isle of Wight, Together for Short Lives, West Midlands Paediatric Palliative Care Network

Child and Young Person's Advance Care Plan

This document is a tool for discussing and communicating the wishes of a child, young person, parent(s) and/or their family. The plan is also designed to record the wishes of families for their baby (neonate or infant).

In addition to recording a concise record of the advance plans it is designed to provide a rapid overview, of key decisions, to the attending carers, should an emergency situation arise when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

It is a collaborative document with representation including the South Central and Wessex, West Midlands, North West, Kent and the South West for shared decision making between families and clinicians.



Child & Young Person's Advance Care Plan (CYPACP)

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Name: Patient's name
 DOB
 Hospital No. 0123456 NHS No. 012345

Wishes du
 Child's / Young Per
 (professional/non-profes

Contacts

Name	Patient's name	Date of Birth	
Known as		Interpreter needed	<input type="checkbox"/> Yes <input type="checkbox"/> No
First Language		Interpreter contact	
Home Address	Address Line1 Address Line2 Address Line3	Postcode:	M19
Telephone Numbers:			

Family Tree

Name of person/people with parental responsibility (and address if different from above):

Emergency contact number for person/s with parental responsibility:

Other emergency contact No.

Others (e.g. family and friends)

Name	Relationship	Telephone numbers

Emergency contact for professional who knows child:

For use please tick [x] Everywhere Home School Hospital

Date Plan Initiated dd/mm/yyyy Date Review due dd/mm/yyyy

Date reviewed/ amended:	Name & title of lead reviewer	Expected review date (if appropriate)
dd/mm/yyyy		dd/mm/yyyy

Name:	Patient's name	
DOB		
Hospital No.	0123456	NHS No. 012345

Diagnosis and Decision Making

Diagnosis

Main problems and Background information

Social issues (Include if Looked after Child)

Decision Making Process

Basis of discussion / decision-making? (Tick as appropriate) [X]

- Wishes of child/young person with capacity
- Wishes of parent(s) for child on "best interests" basis
- Best interests basis (as in Mental Capacity Act 2005)
- Other (please state)

Comment

Name:	Patient's name		
DOB			
Hospital No.	0123456	NHS No.	012345

Specific Treatment Plans

(Prompt: allergies recorded on Front Cover)

Management of seizures <i>(Please select one option only)</i>	Date of Weight	Weight (Kg)
<input type="checkbox"/> Manage using APLS guidelines	dd/mm/yyyy	Kg
<input type="checkbox"/> Requires a personalised seizure plan below		

Personalised Seizure plan: (drug name, dose and route) please add patient weight used to calculate drug doses		
First Line	after time in mins	mins
Second Line	after further time in mins	mins
Third Line	after further time in mins	mins

Call 999 for emergency transfer to hospital?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
If yes, at what stage		
Description of usual seizure pattern/ types		
Other instructions for seizures		

Management of infection

This section is for community use and may involve instructions to transfer to hospital.
 Contact specialist team and microbiology
 Please record if likely to be neutropaenic or have an immune deficiency
 Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

Instructions for other specific circumstances

Name	Signature	Professional Role	Date
Name	Signature	Role	dd/mm/yyyy

Name: Patient's name
 DOB
 Hospital No. 0123456 NHS No. 012345

Management of a Life Threatening Event

Prompt: allergies recorded on Front Cover

Symptoms and signs to expect (NB Information about diagnosis is on p6)

In the event of a likely *reversible* cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis please intervene and treat actively**. Please also treat the following possible problems actively e.g. bleeding (please state):

A life threatening event may lead to a cardiac or respiratory arrest (cardiorespiratory arrest). If p15 has not been completed, decisions about resuscitation would normally be made on a 'best interests' basis. The presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

In the event of life threatening event (Add comments to clarify wishes)

- Support transfer to preferred place of care if possible Specify
- Maintain comfort and symptom management, and support child / young person and family Specify
- Clear upper airway / mouthcare Specify

- | | | |
|------------------------------|-----------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Facemask oxygen if available. any comment |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Bag and mask ventilation. any comment |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Emergency transfer to hospital if considered appropriate. any comment |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Intravenous access or Intraosseous access. any comment |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Non-invasive ventilation. any comment |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Intubation. any comment |

Comments about feeds and fluids

Other (please state): (e.g. may include specific information if a life threatening emergency happens at school)

Name	Signature	Professional Role	Date
Name	Signature	Role	dd/mm/yyyy



Name:	Patient's name		
DOB			
Hospital No.	0123456	NHS No.	012345

Wishes during End of Life

WISHES AROUND THE END OF LIFE

Priorities of care including preferred place for care of child /young person

Spiritual and cultural wishes

Other child/ young person & family wishes, e.g. what happens to possessions?

Organ & tissue donation (see separate guidance on web link <http://www.organdonation.nhs.uk>)
 National contact numbers. 0300 123 2323
 Regional contact numbers.

Funeral preferences

Seek detailed information or further advice if needed

This page has been discussed with child / young person/ parent/ carer:

Professional:
(full name and job title/initials)

Date

dd/mm/yyyy

If page not completed please comment on reasons

Signature Page

Note the signatures apply to pages 4 - 9 only

Who has agreed and supports the plan?

(Doctors must add GMC number after the signature)

Lead Clinician		
Name		
Professional Registration Number	Role:	
Signature	Date:	dd/mm/yyyy

Others included in the decision making. (also see p 14)

--	--	--

Young Person
 (if appropriate; optional) (to ensure their opinions have been included in the decision making)

Name	Signature	Date
		dd/mm/yyyy

Person/ Persons with parental responsibility (see page 4)
 (to ensure their opinions have been included in the decision making)

Name	Signature	Role	Date
1			dd/mm/yyyy
2			dd/mm/yyyy
3			dd/mm/yyyy
4			dd/mm/yyyy
Other			
1			dd/mm/yyyy
2			dd/mm/yyyy
3			dd/mm/yyyy

Clinicians have a duty to act in a patient's best interests at all times.

If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person. The child/young person or parents /guardian can change their mind about any of the preferences on the care plan at any time.

012345



Name:	Patient's name		
DOB			
Hospital No.	0123456	NHS No.	012345

Additional Notes



Name:	Patient's name	
DOB		
Hospital No.	0123456	NHS No. 012345

Distribution List (Key Contacts)

The co-ordinator is responsible for the distribution of the CYPACP, for bringing it to the attention of professionals, and for circulating any updates to it:

Name of Co-ordinator	Contact Details
----------------------	-----------------

24 hour contact number available: (record p14) Yes No

NB: The child and family will hold a full copy of their plan
A full photocopy of the plan to: (include date sent and by whom)

	Name and contact details	Date sent and by whom
<input type="checkbox"/> Local Emergency Department		dd/mm/yyyy by
<input type="checkbox"/> Children's Community Nursing Team		dd/mm/yyyy by
<input type="checkbox"/> Hospice		dd/mm/yyyy by
<input type="checkbox"/> Lead Paediatrician (refer to p14 for specialists involved)		dd/mm/yyyy by
<input type="checkbox"/> GP		dd/mm/yyyy by
<input type="checkbox"/> Other		dd/mm/yyyy by
<input type="checkbox"/> Other		dd/mm/yyyy by

Other professionals who require either a full photocopy, or need to be made aware that the child has a plan (please state which):

	Full photocopy= Aware of plan=	FP / A	Name and contact details	Date sent and by whom
Hospital (ward or assessment unit)				dd/mm/yyyy by
Respite /Short Break Care provider				dd/mm/yyyy by
GP Out of Hours				dd/mm/yyyy by
Ambulance Control				dd/mm/yyyy by
School Nurse				dd/mm/yyyy by
School				dd/mm/yyyy by
Transition				dd/mm/yyyy by
Social Services				dd/mm/yyyy by
Other (e.g. CDOP, Coroner, or EOL Register)				dd/mm/yyyy by
Other (e.g. Hospital Specialists see p14 for contact details; list specialties only here)				dd/mm/yyyy by



Name:	Patient's name		
DOB			
Hospital No.	0123456	NHS No.	012345

If the child / young person dies
(Please contact the following people)

Co-ordinator responsible for the distribution of the CYPACP and bringing to the attention of professionals that the child has a plan.

Details			
24 hour contact number available:	<input type="checkbox"/> Yes	<input type="checkbox"/> No	Phone No.

	Name and contact details
<input type="checkbox"/> Parents/Guardians	
<input type="checkbox"/> General Practitioner	
<input type="checkbox"/> Lead Paediatrician	
<input type="checkbox"/> Hospice	
<input type="checkbox"/> Organ and Tissue Donation team	
<input type="checkbox"/> Other (Rapid Response Team)	
<input type="checkbox"/> Other (ED/ Childrens Ward)	
<input type="checkbox"/> Other	
<input type="checkbox"/> Other	

Other professionals who have either a full photocopy (FP), or are aware (A) that the child has a plan (please see page 13 and below).

NB Where multiple hospital specialists are involved in care it is the responsibility of the lead paediatrician/ lead clinician to inform them of the death; please list names and speciality below and name of person who will inform them.

Name:	Patient's name		
DOB			
Hospital No.	0123456	NHS No.	012345

Management of Cardiorespiratory Arrest

(Including DNACPR)* *Delete if not appropriate

Child's Name	NHS No.
<input type="checkbox"/> Cardiopulmonary Resuscitation status (CPR) has not been discussed attempt CPR unless clearly not in the best interest of the child/ young person (Only a senior clinician may make this decision)	
<input type="checkbox"/> Cardiopulmonary Resuscitation status has been discussed and the following has been agreed:	
Diagnosis and reason(s) for decision (also see p6)	
Ambulance Directive	

Enter X in selected box then select text and strike through (or delete) content in other boxes:

Attempt full Cardiopulmonary Resuscitation	OR	Attempt Cardiopulmonary Resuscitation with modifications below:	OR	DO NOT attempt Cardiopulmonary Resuscitation DNACPR																
<input type="checkbox"/> Select Attempt CPR as per Resuscitation Council (UK) guidelines. detail		<input type="checkbox"/> Select <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%;">INTUBATION</td> <td style="width: 15%;"><input type="checkbox"/> Yes</td> <td style="width: 15%;"><input type="checkbox"/> No</td> <td style="width: 40%;">detail</td> </tr> <tr> <td>AIRWAY AND BREATHING</td> <td colspan="3">detail</td> </tr> <tr> <td>CIRCULATION</td> <td colspan="3">detail</td> </tr> <tr> <td>PICU</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> <td>detail</td> </tr> </table> detail	INTUBATION	<input type="checkbox"/> Yes	<input type="checkbox"/> No	detail	AIRWAY AND BREATHING	detail			CIRCULATION	detail			PICU	<input type="checkbox"/> Yes	<input type="checkbox"/> No	detail		<input type="checkbox"/> Select DNACPR Patient-specific supportive care is documented on pages 7, 8 and 9 detail
INTUBATION	<input type="checkbox"/> Yes	<input type="checkbox"/> No	detail																	
AIRWAY AND BREATHING	detail																			
CIRCULATION	detail																			
PICU	<input type="checkbox"/> Yes	<input type="checkbox"/> No	detail																	

Clinician (usually lead clinician)	2nd Clinician (2 nd Signature may be required if lead clinician has not signed above and countersigns at a later date)
Clinician Name Name	Clinician Name Name
Professional Role/ Grade	Professional Role/ Grade
GMC/ (NMC) No.	GMC/ (NMC) No.
Signature	Signature
Date dd/mm/yyyy	Date dd/mm/yyyy