Summary for the Focus Group

As part of an in-depth study of amputees of Hong Kong, the Hong Kong Association of Amputees Ltd. (HKAAL) conducted focus groups and interviews on 1 July 2017. A total of 8 amputees and 9 family members and friends of amputees participated in this study. The key findings are presented in this report.

作為深入研究香港截肢者的一部分,香港截肢者協會於 2017 年七月一日 向八位截肢者及 9 位他們的家人和朋友進行了聚焦小組訪談,並把主要的 研究結果在這報告內發表。

Key Findings on Amputees

截肢者的主要研究發現

- A. The Life of Amputees A. 截肢者的生活
 - (1) Amputations could be the result of accidents, chronic diseases or infections. Those who lost their limbs due to accidents would generally perceive greater impact than those who were amputated due to chronic diseases or infections. The former felt their amputations had turned their lives upside down whereas the latter might actually feel relieved after their amputations.

(1) 接受截肢手術的原因可能是意外受傷,慢性疾病或受細菌 感染。因意外受傷的截肢者比慢性疾病或受細菌感染的感受更 大的影響。前者覺得他們過往的生活全被攪亂,而後者則在截 肢手術後反而感到放心。

(2) All amputees must endure great pains to adapt to their prostheses, to overcome the frustrations they faced everyday and to regain their mobility, all in the hope that someday they could function well enough to take their rightful place in society.

(2)所有截肢者都一定經歷極大的痛楚去適應他們的義肢,去 克服他們每天面對的挫折和恢復他們的活動能力,他們都渴望 有一天他們能有足夠能力重投社會。

(3) The road to recovery is two-dimensional: the body and the mind. Almost every participant stressed the important role their mind set and attitude play in their recovery journey. Acceptance of what happened, readiness to do what is required and perseverance are the necessary ingredients.

(3) 康復的路是雙軌道的:身體和心態。幾乎每一位參與者都强調思想與態度在康復旅途上扮演著很重要的角色。接受現實、按需要**作好準備**,和毅力**都**是必須的元素。

- (4) They faced many obstacles along the way. The government provided only limited support. Family and friends are the .crucial sources of support, motivation, care and love.
 (4) 他們在康復過程中都面對很多障礙。政府只能提供有限的 支援。家人和朋友是支持、動力、關懷及愛心的關鍵來源。
- (5) While most would lament their loss of personal freedom and the quality of life they enjoyed before amputation, some actually pointed out the things they have gained from amputation, the proverbial "silver lining" : they were touched by the love of family and friends; they met many new and amazing fellow amputees; they became more confident and optimistic; and they discovered a new fulfilment in life.

(5)雖然很多人會哀嘆他們失去在截肢前享有的個人自由和生活質素,但有些人卻能夠指出他們從截肢後獲得的一線希望奧與慰藉:他們被家人及朋友的愛所觸動、他們認識許多截肢者,並成爲知己、他們更有自信心和變得樂觀,並發現人生有新的路向。

- B. Their Wishes and GoalsB. 他們的盼望與目標
 - (1) Being able to care of oneself, to live independently and to be a productive member of society is a wish held by every amputees.
 - (1) 能夠照顧自己、獨立生活和在社會上有貢獻是每一位截肢者的希望。
 - (2) Helping and sharing their experience with other amputees also places high on their wish list. They wish to meet and provide the new

amputees and their family with help and guidance that they themselves had not received when they began their journey.

(2) 其他截肢者及與他們分享經驗亦是在希望清單中較高位置。他們希望與新的截肢者和他們的家人會面,提供自己在開始康復旅程時未曾得到的幫助和指引。

(3) Those who are competitive by nature would hope to train harder and further build their strength.

(3) 具有較強能力的截肢者則希望加強鍛煉以提升自己的能力。

- C. Roles of the Government/Community C. 政府與社會的角色
 - (1) These amputees feel that they are being viewed as oddities by members of the general public. They feel uncomfortable being stared at. They would prefer to be viewed and treated as ordinary people. The public should be informed and educated in this regard.

(1) 截肢者覺得他們被大衆投以怪異的眼光。他們對被人注目 而感到不舒服。他們希望別人以正常人的目光看待他們。大家 應體諒及包容。

(2) Job opportunity for amputees is limited, especially for non-skilled positions. Employers must not discriminate amputees solely on their physical appearance or handicap. It is the government's role to stop and prevent such discriminations.

(2) 截肢者的工作機會是有限制的,尤其是非技術性的職位。 雇主不應只基於他們的生理外貌或殘障而歧視截肢者,政府有 責任禁止及防止這種歧視。

(3) Access to public facilities and transportations in Hong Kong is not friendly to amputees. This lack of consideration for amputees hampers their ability to regain mobility. It deters their progress to return to society as productive members. Clearly, the government has a responsibility in this area.

(3)在香港使用公共及交通設施對截肢者來說並不**方便**。這樣 **漠視**截肢者的需要會窒礙他們重新恢復活動力,更會延遲他們 重投社會的勞動力。這明顯是政府的責任。

(4) As far as rehabilitation is concerned, these amputees received very little help from the government. There were inadequate follow-up after fitting of prostheses. Amputees received little information on how to prepare for a life that was new to them. There were no guidelines or roadmap for amputees as they embarked on the most difficult and exhausting journey of recovery.

(4) 從康復者而言,政府對截肢者的幫助是非常少。他們在義 肢接駁後的跟進服務並不足夠,截肢者在如何適應日後生活的 資訊很缺乏,在他們康復路途上亦全沒有指引或提示,使他們 感到非常困難和疲乏。

- (5) A successful rehab program should provide all the information helpful to the amputees and their family at the start. It should engage the amputees early on in an intensive training for physical fitness. Counselling for both the amputees and family members is paramount.
 (5) 一個成功的截肢康復計劃應該在開始階段便提供所有有用的資訊給予截肢者和他們的家人。它必須讓截肢者儘早參與體能的強化訓練。對截肢者及家人的輔導更是首要的。
- (6) In order for the government to be more effective in aiding the amputees, it should consider engaging amputees in key consultative positions and hiring amputees in care-giving facilities.
 (6) 為使政府可以更有效地幫助截肢者,它應該考慮讓截肢者 擔當主要的輔導角色,並聘用他們投入護理工作。

Key Findings on Family and Friends of Amputees 截肢者的家人及朋友的主要研究結果

- A. Life as care-givers
 - A. 擔當護理人員的生活方式

(1) With very few exceptions, the key family members continue to work while taking care of the amputees. They need to balance the time between work and caring for the amputees. While it is desirable for the care-givers to assist and to coach the amputees to perform the daily tasks instead of doing the tasks for them, it can even be more timeconsuming and require infinite patience.

(1) 除了**少數個別**例子,家庭成員都**需要**一邊工作一邊照料截 肢者。他們需要平衡地分配工作和照顧時間。雖然由照顧者協 助和教導截肢者自行處理日常生活的事宜更為理想,可是這需 要更多的時間和無比的耐性。

- (2) An important task for the family members is to keep abreast of new development in wellness and rehab treatment and prosthesis technology.
 (2) 家人的其中一個重要任務是對復康療程及義肢技術的新發 展, 與時並進。
- (3) Then there are amputees with strong egos who were slow in accepting the fact that they would need help in performing even the simplest task of personal grooming. This made the job of the care-giver much harder than it was.

(3) 然而有些截肢者卻因自尊心太強的關係而導致接受現實的 速度很慢,甚至連個人梳洗等簡單事情都需要幫忙。這使護理 人員的工作更加困難。

(4) Adapting to the prostheses was a long and painful process of which the amputees were ill prepared for. They might have unrealistic expectations on how quickly they could recover or how well their prostheses would perform. The occasional setback led to disappointment and despair. The family members and friends would be instrumental in providing encouragement and motivation for the amputees and keeping their emotions on an even keel. Most caregivers would consider this their most challenging task... and also the most rewarding one.

(4) 截肢者適應使用義肢的過程是漫長和痛苦的。他們或許對 自己康復的速度和義肢的功能有錯誤的期望。偶然的挫折往往 會令他們失望和沮喪。家人及朋友這時可以就鼓勵截肢者起作 用,穩定他們的情緒。大部分護理人員都會視這任務視作最具挑戰性及成功感。

- (5) As the amputees made steady progress on their journey of recovery, they became stronger, more confident and they treasured life in a way they never did before. Their family and friends witnessed this transformation and found it amazing and inspirational.
 (5) 當截肢者在康復過程中有穩步進展,他們會變得更堅強, 更有自信和比前更珍惜生命。他們的家人及朋友見證這轉變, 都會感到驚訝和鼓舞。
- B. The roles of the care-givers 擔當護理人員的角式
 - (1) The family and friends of amputees provide the amputees with something the government has so far overlooked: encouragement, motivation and hope. They must take on the role of "counsellors" to the amputees. As the amputees progressed through the different stages of recovery (denial, acceptance, adaptation, fulfilment), they went through emotional ups and downs. The care-givers must be fully aware and would strive to become the beacon, the port in a storm for the amputees.

(1)家人及朋友為截肢者提供政府到現時仍忽略的東西:鼓勵,動力和希望。他們必須承擔截肢者的心理輔導員。當截肢者經過復康的不同階段(即否認、接受、適應,實行)時,會經歷時高時低的情緒困擾。護理人員必須全面瞭解並努力為截肢者作指路明燈和避風港。

(2) The amputees were facing a life-changing experience that was painful, humbling and frustrating. Some would become bitter, withdrawn, despondent. To communicate with the amputees effectively, the caretakers must learn to become superb communicators: to listen without judging; to console without pitying; to persuade without demanding.
(2) 截肢者曾經歷痛苦、震撼和沮喪的生命改變。有些會變得怨憤,退縮和沮喪。要有效地與他們溝通,護理人員必須學習成為高超的溝通者 - 不帶批評的聆聽,不帶可憐的安慰話, 不帶命令的相勸。

(3) In order that the amputees may regain their mobility and confidence to re-join society in due course, the care-givers would play the role of the coach: keep track of the progress of the amputees; maintain their positive attitude; seek helpful information and success stories to share with the amputees; give the extra push where needed; be their cheerleaders and celebrate their success.

(3) 為要使到截肢者恢復他們的活動能力和自信,以便在適當的 時候重投社會,護理人要擔當教練的角式 - 跟進他們的康復進 展,保持他們的正面態度、尋找有用資料及成功案例與他們分享, 在有需要時給予額外的推動,並做他們的**啦啦**隊隊長與及慶祝 他們的成功。

- C. Lessons the care-givers like to share C. 護理人員願意分享的課題
 - (1) We must maintain a positive mind set ourselves if we are to succeed in helping the amputees. While some medical personnel are very supportive, others might be overly conservative in their assessment. Do not take their words on face value. There are no miracles, only perseverance.

(1) 若我們想成功幫助截肢者,我們自己一定要保持正面的思維。雖然有一些醫護人員是十分願意給予支援,但有些卻對復康評核過份保守。不要盲目接受他們所說的。**康復**是沒有奇跡的,只有毅力。

- (2) Believe in rehabilitation. Seek aid from Social Welfare Department. Get all the information and prepare well before discharge from the hospital.
 (2) 相信復康。尋求社會福利處的幫助,搜尋所有相關資料, 並在出院前做足準備。
- (3) Get involved in support groups such as HKAAL(3) 參與支援團隊,如香港截肢者協會。
- D. What the government should do D. 政府該做什麼

- (1) Provide funding for prostheses of better quality.
 - (1) 撥款資助好質素的義肢。
- (2) Disseminate information on support organizations such as HKAAL.(2) 散播支援組織(如香港截肢者協會)的資訊。
- (3) Collect and disseminate information on amputees care/support from countries which are more advanced in this regard.
 - (3) 從不同國家收集和散播較先進的截肢者護理/支援資訊。
- (4) Educate the public on how they should view and relate to amputees.(4) 教育民衆應如何看待截肢者和如何與他們相處。