

**Community Integration for
People with High Level
Tetraplegia**

协助高位脊瘫病者重返小区

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Tai Po Hospital
大埔医院



High Level Tetraplegia

高位脊癱



Being cared
被照顾

Pressure sores
压疮

Dependent
被动无助

Bed bound
终日躺在床上

Depression
压抑

**QOL, life satisfaction, well being,
participation, community integration**

Home bound
终日被困家里

Contracture
挛缩

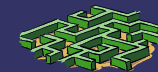
Wheelchair
轮椅

Social isolation
与外隔绝

- Decreased *QOL* and diminished *well-being* are often related to the SCI population
(Charlifue et al, 1999; Leduc and Lepage, 2002; Putzke et al, 2002)
- QOL, however, has *not* been shown to be strongly related to the *level of injury*
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- Rather, more associated with various *psycho-social factors*
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- the extent of *community participation*
(Kemp and Vash, 1971; DeVivo and Fine, 1982; El Ghatit, 1987; Chaves et al, 2004; Krause et al, 2004; Whiteneck et al, 1992, 2004)
- and *physical and social environmental factors*
(Whiteneck et al, 1992, 2004)

Community Integration for People with High Level Tetraplegia 协助高位脊髓病者重返小区

- Special Rehab Goals for High Level Tetraplegic Patients (In-patient phase) 康复目标
- Preparation for Home Discharge 计划回家
- Use of Assistive Equipment 使用康复辅具
- Return to Community 重返小区
- Discussion 讨论



Specific Rehab Goals for SCI Patients

康复目标



Improve QOL
Community re-integration
Resume/re-establish life roles

COMMUNITY

提高生活质量
重返小区

Psychosocial adjustment
Caregiver stress
Home Ax/ modification

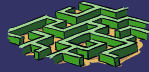
HOME

心理社交及
照顾者之适应

Limbs positioning
Body positioning & special seating
Communication
Functional performance/ limitation

PERSONAL

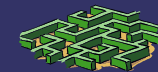
减退并发症
尽展所能



Specific Rehab Goals

康复目标

- Limbs positioning and splintage 肢体摆放及使用支架
- Body positioning and special seating 体位摆放及特别座椅的应用
- Communication 建立沟通模式
- Psychosocial issues 心理社交方面的关注
- Caregiver's training 照顾者的教育及训练
- Preparation for home discharge 计划回家
- Community re-integration 重返小区



Limb Positioning & Splintage

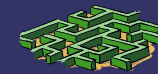
肢体摆放及使用支架



Body Positioning and Special Seating

体位摆放及特别座椅的应用

- ▷ To achieve optimal posture in sitting to maximize breathing capabilities
- ▷ Position for functional training/ performance
- ▷ Facilitate self care
- ▷ Enhance self image



Sit-out Programme 起坐计划

- Liaison with nursing staff
- Daily bedside sit out on special positioning chair
- Use abdominal binder and compression stocking for cardio-vascular training/ prevention of postural hypotension
- Continuous monitoring the SpO₂ and BP



Communication 建立沟通模式

- Tracheostomized or ventilator-dependent individuals may have communication impairments due to impaired vocal cord function or laryngeal nerve



- Intervention goals:
 - To facilitate the communication of thoughts, needs, wants and ideas



▷ Non-verbal

- Facial expression
- Eye blink
- Lip reading
- Gestures
- Head movement (for yes or no response)
- Body language
- Sign language

▷ *Effective for communication of basic needs*

▷ Verbal

- Can be attained if the persons have at least partially intact vocal cord function

▷ *Effective for social communication*



Psychosocial Issues

心理社交方面

- ▷ Sudden role changes, both patient and family members
- ▷ Being dependent on self-care and all other ADLs, leisure pursuits
- ▷ OT Intervention
 - Enhance coping skills, facilitate adaptation and stages of change
 - Increase self-care independence and home care through use of assistive devices and equipment; appropriate prescription and training
 - Leisure exploration (age and pre-morbid lifestyles), web surfing, MSN, QQ, computer games
 - Introduce peer support, explore and experience community living possibilities



Psychological Preparation and Caregiver(s) Training

家人及照顾者的教育及训练



- Education on use of various assistive equipment
- Proper handling techniques and emergency handling

- Enhance care giving skills
- Reduce care giving stress

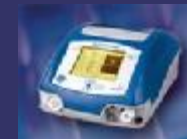


Ventilator Dependent Clients

使用氧气机



- Liaise with respiratory equipment suppliers
- Training and practice on ventilator use, maintenance and trouble shooting
- Portable unit for outdoors use and limitation



Other Tech Points 特别关注项目

- For ventilator-dependent clients:
 - Ensure adequate ventilation
 - Free of fire hazard
 - Bedside table or nightstand to hold ventilator by bedside
 - Adequate electricity supply to support additional demands of respiratory equipment
 - Emergency contact ready at hand



Preparation for Home Discharge 计划回家

- Psychological preparation for both patients and caregiver(s) or significant others
- Early involvement of caregiver(s)
- Home assessment and modification
- Recommendation on appropriate assistive equipment
- Use of transportation
- Weekend home leaves/ trials
- Community/ communal area visits



ADL 日常生活方面

- ▷ How
 - Special procedures and positions
- ▷ What
 - Special equipment required
- ▷ Who
 - Caregiver(s), maid or any other family member(s)
- ▷ Where
 - At home, on bed, chair or in the bathroom; lying or sitting position
 - What about in the community, use of community facilities



Home Visits 家访 - Aims and Objectives

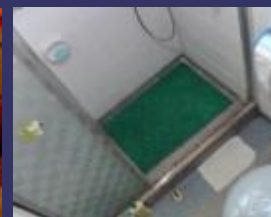
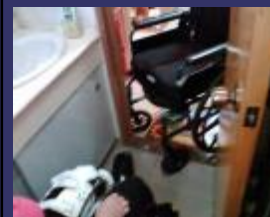
1. To better understand patient's living environment – floor size, accessibility, modifiable?
2. To advise on proper handling skills according to on-site situations
3. To assess patient's functional performance in home environment, further training implications
4. To assess caregiver's skills
5. To recommend appropriate home care equipment
6. To better communicate with patient and family/carer on future home care issues



Home Assessment and Modification

家居环境评估及改造

- Evaluate and modify the existing home environment to accommodate the use of necessary home care equipment
- Accessibility/barrier-free vs purpose-built



Recommendation on Home Modifications

建议家居环境改造

- Practicality 实用性
- Feasibility 可行性
- Privacy 私隐度
- User's perspectives 用家角度



Communal Areas 公用地方



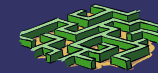
Use of Assistive Equipment 使用康复辅具

- To enhance patients' ADL performance and self care independence
- To alleviate family/caregiver's burden of care
- To facilitate community living/ participation and community integration
- To enhance QOL



Equipment Recommendation 建议使用辅具

- Accessibility 可用性
- Manoeuvring space 使用空间
- Turning space 转动空间
- Storage space 存放空间
- Acceptance 接受程度
- Affordability 可负担程度



Pyramid of AT Prescription 建议使用康复辅具



Various Types of Assistive Equipment for SCI Patients



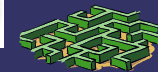
Consideration for Hospital Beds 使用家护床的考虑

- ▷ Crank position or electric
- ▷ Space for (hoist) transfer
- ▷ Activities on bed – bladder and bowel management, spasticity management
- ▷ Types of hoist used

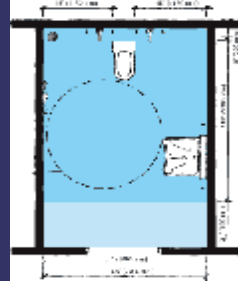
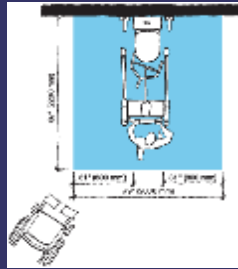
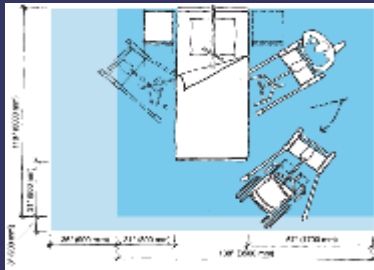
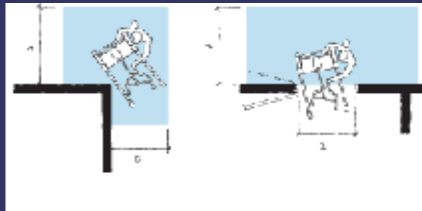


Consideration for Hoists 使用起重机的考虑

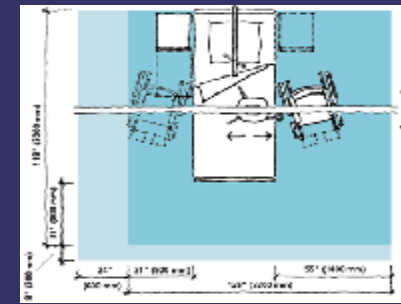
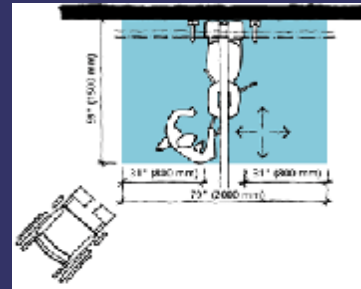
- ▷ How and where to use
- ▷ Type of accommodation (rented/ private/ temporary/ permanent)



Mobile Hoist

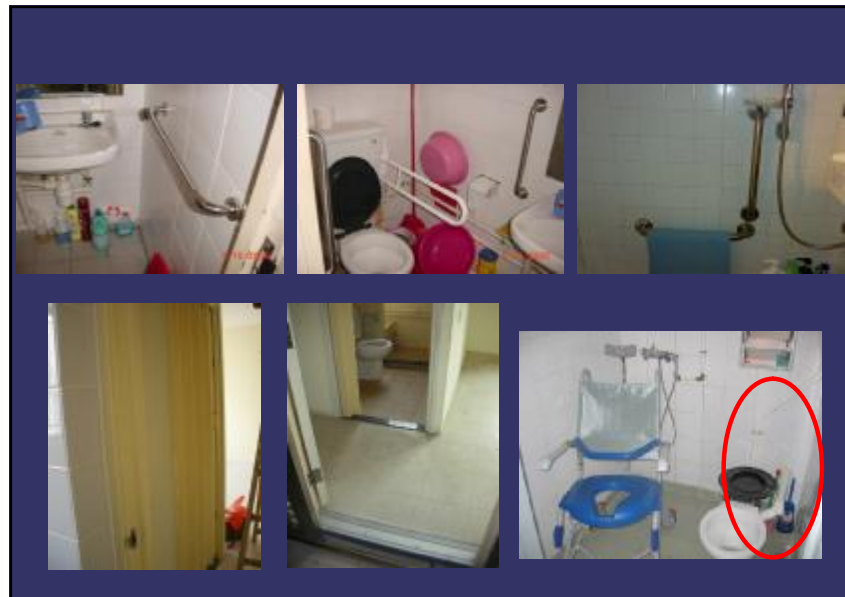


Ceiling Hoist

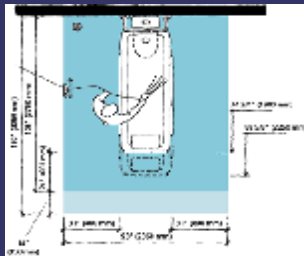
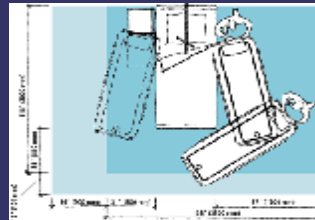
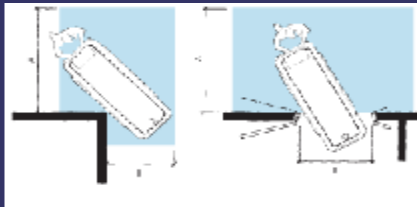


Consideration for Shower Chairs/Trolleys 使用浴椅/床的考慮

- Moving or stationery
- Accessibility and turning space
- Can it be fit in existing toilet/bathroom



Shower Trolley



Concerto – Hydraulic (Technical Information)

Safe working load	150 kg (330 lbs.)
Lifting stroke	320 mm (12 ")
Height, top position to stretcher	570-890 mm (22"- 35")
Weight	74 kg (163 lbs.)
Width (stretcher)	650 mm (25 ")
Total width (incl. side supports)	760 mm (30")
Total length (different stretcher lengths)	1600 mm (63")
	1850 to 1950 mm (73- 77")
	2250 mm (88 ")
Length of chassis (incl. wheel frame)	980 mm (38 ")
Height of chassis	150 mm (6")



Power Wheelchair Option 选用电动轮椅

- ▷ Special control switch options – mode of control
- ▷ Special positioning function – tilt/ recline/ or both
- ▷ Other special requirement – vent tray

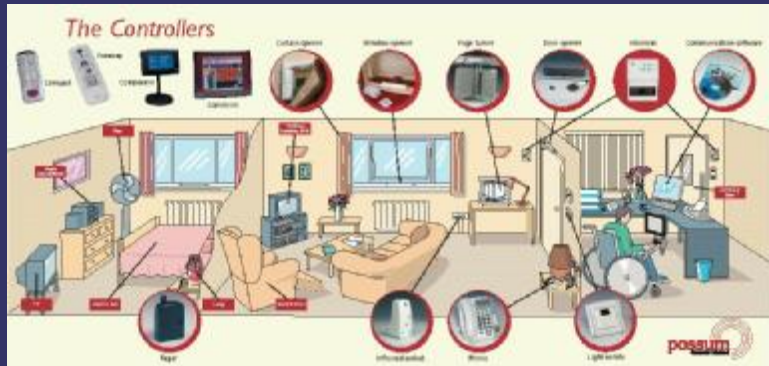


Postural Support and Seat Cushion 身体的承托与坐垫的配合





Environmental Control Unit (ECU) 环境操控系统



Smart Living 智能家居



Community Re-integration

重返小区

- ▷ Community living skills / accessibility
- ▷ Use of transportation/ Disabled driving
- ▷ Community resources
- ▷ Vocational / avocational exploration



Vocational / Avocational Exploration

职能发展

- ▷ Explore and facilitate
 - web-based/online training /working opportunities,
 - diversionary pursuits,
 - leisure interests,
 - local community resources, and
 - use of adaptive equipment and environmental modifications to enhance functional performance in vocational/ avocational pursuit
 - return to studies/ work



Social Resources
小区资源 / 自助组织

- Community resources
- Local specialists
- Peer support groups



康复资源协会



香港伤残青年协会



香港残疾人奥委会暨伤残人士体育协会



香港康复力量



柏力与确志协会



工程及医疗义务工作协会



路向四肢伤残人士协会



自强协会有限公司



香港伤健协会



香港复康联盟有限公司



「傷人」的標籤雖然早已「不」再貼於他們身上，但他們仍要面對種種不便，這並非因為他們是「傷人」，而是因為他們是「傷人」。

「即」使身體殘障，精神亦疲弱，透過騎單車這項運動，不但可以鍛煉體魄，更可以舒展心扉，令他們重新找回自信，令他們重新找回自信。

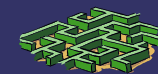
「Sei Kwan」的單車隊，由一群「傷人」組成，他們在「傷人」的道路上，不孤單。

運動助拾自信 勇對人生起伏

Sports for the Disabled in Hong Kong
香港残疾运动员



Case Study
个案研讨



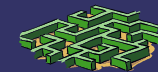
Case Study 个案研讨

- Miss L, F/19
- RTA in China in 1 May, 08
- traumatic cervical cord injury
- C4/5 fracture dislocation
- PSF in China on 16/6/08
- tetraplegia, C 4 ASIA A
- ventilator dependent
- PEG feeding
- Doubly incontinence
- on LT Foley
- ADL totally dependent



Progress 进度

- Phrenic nerve stimulation test on 21/11/2008
- Normal L side and R side absent
- Assess for diaphragmatic pacing
- Frequent complaint of neck pain
- Tolerating sit out on tilted-up position
- Can assess computing device and web surfing



Seating System

Head Support

Back Support

Seat Cushion



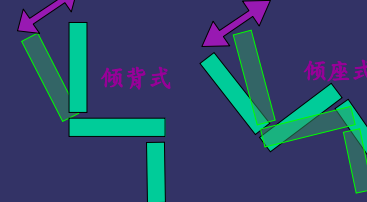
Ventilator Tray for portable ventilator

Tilt-in-Space Wheelchair

For better body positioning and even pressure distribution



Back angle (recline) and Seat angle (tilt) can be adjusted





Seating system prescribed:

Tilt-in-space wheelchair with head support → To facilitate outdoor activities



Ventilator tray for portable ventilator

Use of Computer Access to Promote Psychosocial Well-being

Rationale:

Young age
→ leisure pursuit and possibly distance learning in the future



Long-term goal:

- Internet-surfing
- MSN to network with friends
- Playing games
- Online learning
- Home office, ...

Computer Access

- n **Scanning system** installed in the computer à facilitate operation of the software in computer
- n **Keyboard display** on monitor à Client can perform word processing with scanning system + special switch



Keyboard display



Scanning system

Computer Access --- Input Devices

Adapted Mercury Switch



Head Mouse

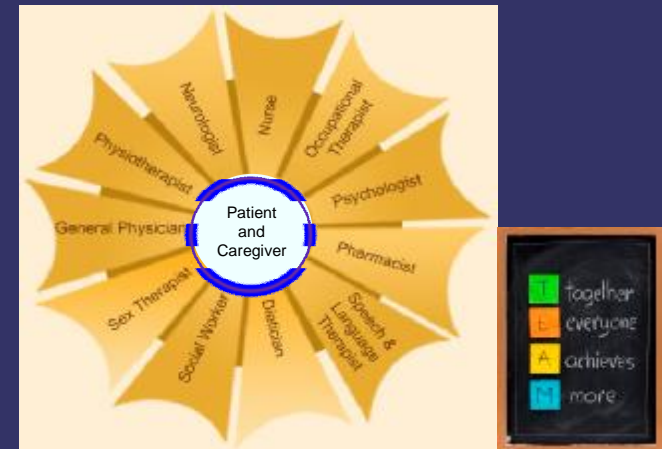


Most Frequently Asked Questions 常见问题

- Psychosocial adjustment
- Worries over future home care issues
- Level of support at home vs professional care in the hospital
- Experience of “emergency” care and handling
- Use of home oxygen, fear of equipment/ power failure
- Home and community accessibility
- Long term financial implication
- Hope for the future

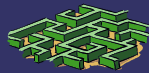


Multidisciplinary Team Approach 医疗团队



TPH Experience in Hong Kong 香港《大埔医院》经验

- ▷ 33 (24 tetra; 9 para) SCI patients from Year 2002 were followed up
- ▷ Our functional outcomes were compared to those in the *American Consortium for Spinal Cord Medicine*
- ▷ Our **FIM motor scores** appeared to be lower and **length of stay was longer** in the tetra group
- ▷ Personal care support from a hired maid and one family member/wife
- ▷ Their average **length of stay** ranged from 145-215 days for the tetra group and around 55 days for the para group

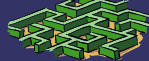


- ▷ Humanistic approach by the rehab team and respect the patients' personal preference
- ▷ Extensive time was required for home modification, compassionate rehousing, funding application and equipment prescription
- ▷ Almost 90% of our SCI patients returned to live in the **community** after a home visit with home modification and/or house transfer/compassionate rehousing
- ▷ Most frequent prescribed assistive equipment include wheelchair (manual or power), seat cushion, commode/shower chair, mobile hoist, hospital bed and mattress overlay
- ▷ Almost all did not return to work/ study immediately after discharge to the community

(Chan & Chan, 2005, *Spinal Cord*; Chan & Chan, 2013, *J of SCI Med*)



- In another study in TPH, ICF model was adopted to investigate “User satisfaction, community participation and quality of life among Chinese wheelchair users with spinal cord injury” (N=31).
- The relationship between SCI, wheelchair users’ satisfaction, perception of their community participation and QoL were investigated.
- Selected items of “Participation Restriction” (d) and “Environmental Factors (e) of the ICF were used to capture how each participant’s community participation was in different environments while using a wheelchair.
- A weak correlation was demonstrated between user’s satisfaction (service sub-scores) and ICF environmental factors (health related professionals).
- A moderate association was, however, observed between social relationship, participation in leisure and driving activities with QoL scores.
- It was, therefore, concluded that *community participation*, in terms of use of transportation, and *human environment*, in terms of friends and peers, were more related to QoL.



(Chan & Chan, 2007, J of SCI Med)

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- and *physical and social environmental factors*

(Whiteneck et al, 1992, 2004)

*To conclude, the ultimate rehabilitation goal for people with (high level) SCI is to facilitate their **community re-integration** and maximize the extent of their **participation** in their “new” life when they return to the community.*

积极参与
重返小区
贡献社会



Thank You! 谢谢!

