



## Quality of Life in Children with Cerebral Palsy

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Children's Hospital  
SingHealth

### Scope of presentation

#### QOL in Children with Cerebral Palsy

- What is cerebral palsy?
- What impacts on QOL in kids with CP
- Rationalising goals for kids with CP



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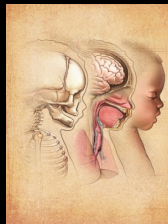


### Understanding Cerebral Palsy

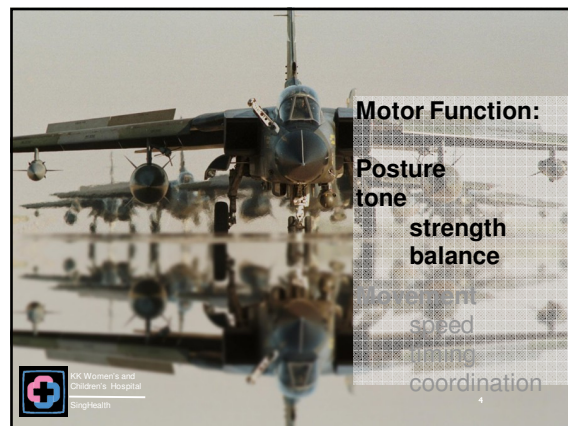
Problem with motor function

*Tone, Movement and posture*

due to injury to the developing  
brain



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#### Motor Function:

Posture  
tone

strength  
balance

movement  
speed  
timing  
coordination



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#### Motor Function:

Posture

tone  
strength  
balance

Movement

speed  
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coordination



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### Understanding Cerebral Palsy

Throwing a ball



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## Understanding Cerebral Palsy

### What problems does the child face?

#### Motor system

gait, mobility  
sitting, standing  
hand function  
feeding difficulties  
squint  
scoliosis  
constipation

#### Associated problems

learning difficulties  
speech, language delay  
epilepsy  
visual impairment  
hearing impairment  
behavioural disorder

## Causes of Cerebral Palsy

#### Prenatal

stroke  
brain malformations  
intrauterine infections  
chorioamnionitis  
intracranial bleed

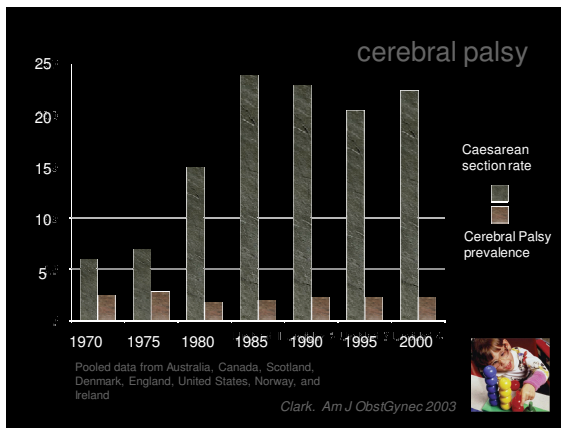
#### Intrapartum

prematurity  
asphyxia  
stroke  
meningitis  
intracranial bleed  
kernicterus

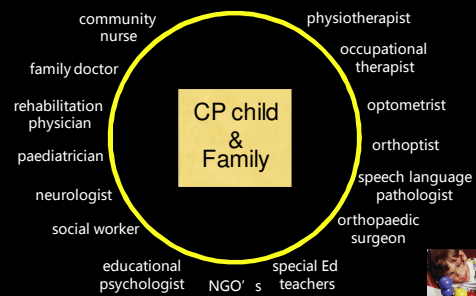
#### Postnatal

anoxia  
meningitis  
non-accidental injury  
stroke

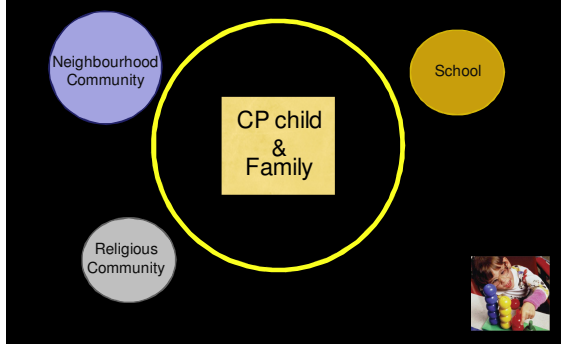
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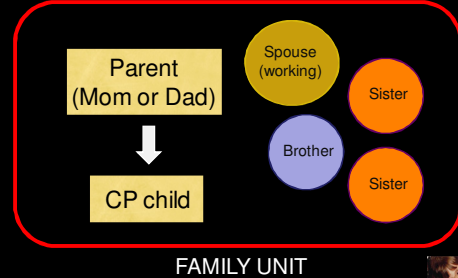
## The CP Management Team



## Living with Cerebral Palsy

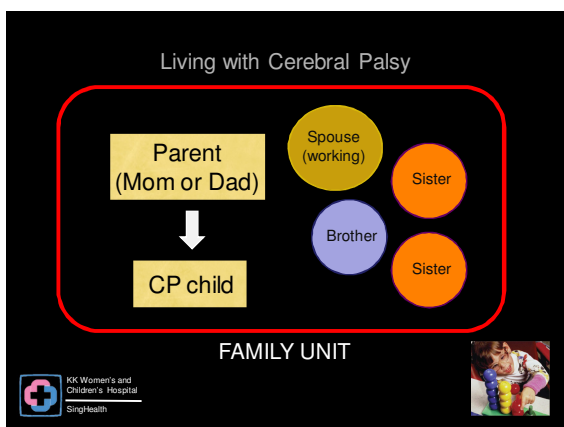
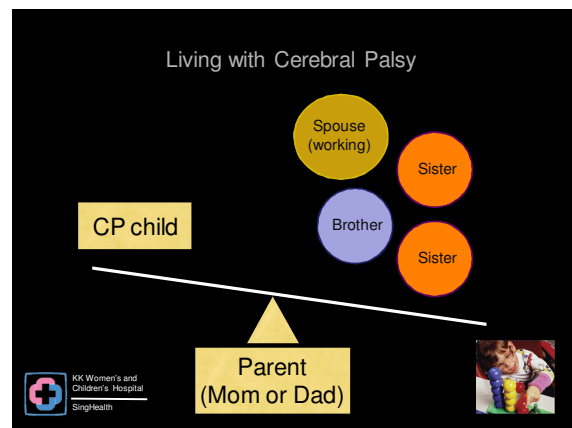
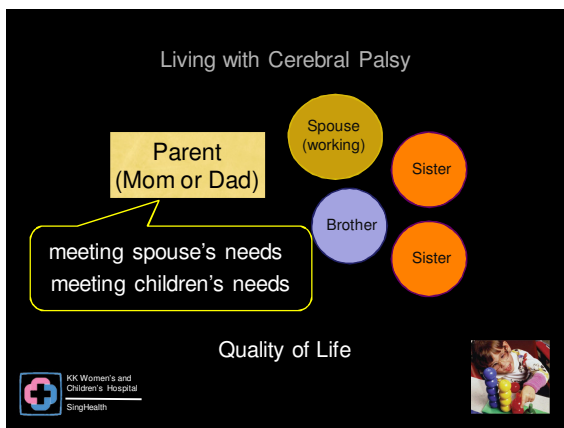
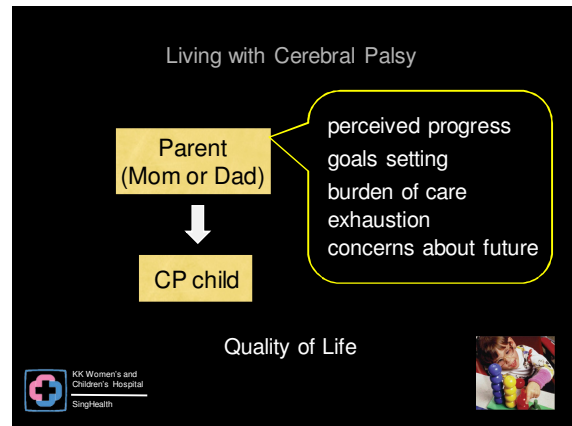
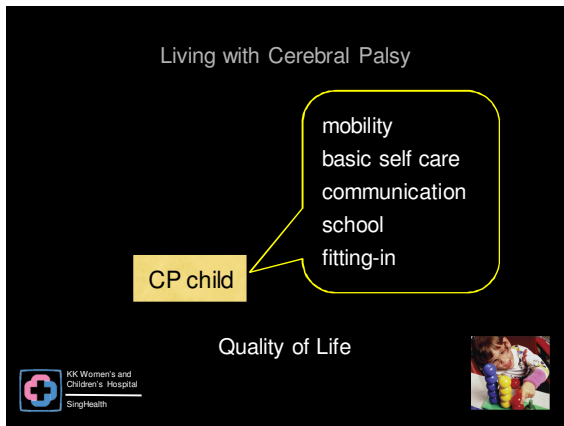


## Living with Cerebral Palsy

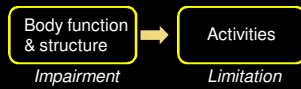


FAMILY UNIT





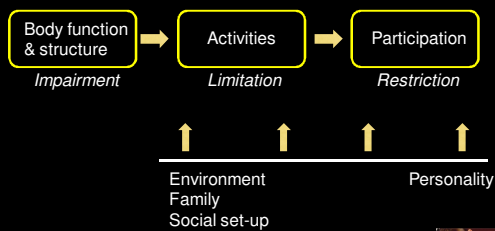
## Disability and QOL



## Disability and QOL



## Disability and QOL



## Measuring Quality of Life

### CP QOL-Child

*CP Quality of Life Questionnaire for children*

### CHQ

*Child Health Questionnaire*

### KIDSCREEN-10

*European Quality of Life questionnaire – 10 domains*



## Measuring Quality of Life

### CP QOL-Child

*CP Quality of Life Questionnaire for children*

- Social well-being and acceptance
- Feelings about functioning
- Participation and physical health
- Emotional wellbeing
- Access to services
- Pain and feelings about disability
- Family health



## Rationalising QOL Goals

### The Kids Who Can

GMFCS I-III

### The Kids Who Need a lot of care

GMFCS IV-IV

Severe cognitive impairment

Bed bound

Tube feeding

Visual impairment



## Rationalising QOL Goals

### The Kids Who Can

GMFCS I-III

+/- some  
learning issues  
visuo-motor issues  
manual dexterity  
epilepsy

mobility  
basic self care  
communication  
school  
fitting-in



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## Motor ability and QOL

CP QOL-Child	GMFCS I	GMFCS II	p value
• Social well-being, acceptance	71	67	0.25
• Feelings about functioning	65	66	0.77
• Participation & physical health	67	61	0.16
• Emotional wellbeing	69	66	0.54
• Access to services	28	43	0.02
• Pain, feelings about disability	62	50	0.01
• Family health	63	51	0.02



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## rehabilitation

### Important

- physiotherapy
- occupational therapy

### techniques

- Bobath's neurodevelopmental therapy
- Peto's conductive education
- sensory integration therapy



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## rehabilitation

### Important

- Aids and adaptations



## rehabilitation

### Important

- speech therapy
- behavioural therapy
- medical treatments
  - muscle relaxants - baclofen
  - seizure medications



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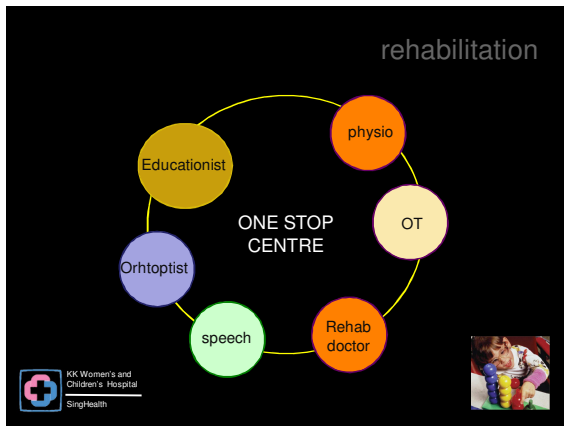


## rehabilitation

### sometimes used

- medical treatments
  - botulinum toxin
- surgical treatments
  - orthopedic surgery - contracure release, hip surgery
  - neuro surgery - dorsal rhizotomy
- complimentary therapies
  - pool time
  - hippotherapy
  - music therapy
  - massage
  - acupuncture





## Rationalising QOL Goals

**Child**    **Caregiver**

keeping healthy  
optimise nutrition  
prevent deconditioning  
prevent pain

**The Kids Who Need a lot of care**

- GMFCS IV-IV
- Severe cognitive impairment
- Bed bound
- Tube feeding
- Visual impairment

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## Rationalising QOL Goals

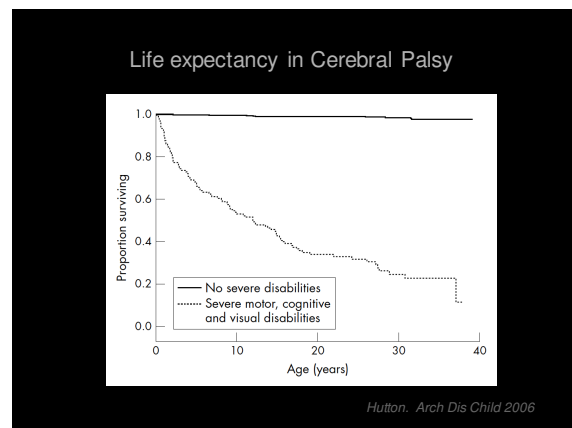
**Child**    **Caregiver**

facilitate & ease care  
anticipate complications  
respice  
time for spouse, other kids  
mental health  
social integration

**The Kids Who Need a lot of care**

- GMFCS IV-IV
- Severe cognitive impairment
- Bed bound
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## management

**Goals of rehabilitation**

Severely impaired children - improve *Quality of Life* for family

- feeding - method, time to feed
- mobility
- manage seizures
- prevent complications that impact on long term care:
- respite care
- hip dislocation, scoliosis

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## management

**Severely impaired children**

- Gastrostomy tube for feeding

ADAM

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### rehabilitation

not

- "medical treatments"
  - health supplements: Palsotab, Ceretitin, Nootropil
  - stem cell therapy
- rehabilitation techniques
  - Glenn Doman (Institute for Achievement of Human Potential)
- complimentary therapies
 

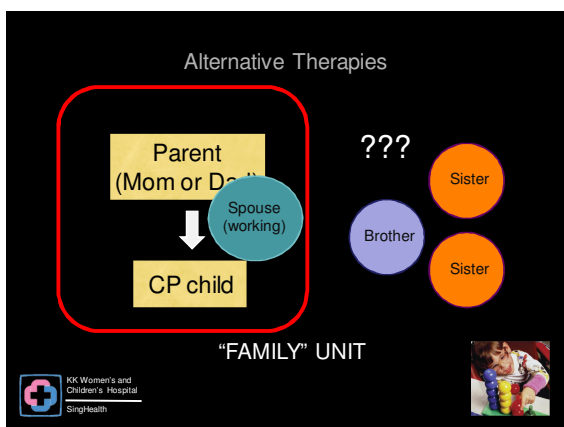
EEG neurofeedback	biofeedback
magnetic therapy	chiropractic manipulation
electrical stimulation	cranosacral therapy
special diets	hyperbaric oxygen

### rehabilitation

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## Practical Issues We Face

- CP management teams
- Resources for aids and adaptations
- School
- Respite care

### Growing up with CP

- What happens after school is over?
- Transition to Adult care



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Gardens  
by the Bay

Thank You