IPWSO International Prader-Willi Syndrome Organisation

Health ECHO
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The Power of Exercise for People with PWS

Georgina Loughnan
Prader-Willi Syndrome Clinic
Royal Prince Alfred Hospital
Sydney, Australia

Physical Features seen in People with Prader-Willi Syndrome (PWS)

Clinical Features

- Lower muscle tone
- Decreased % muscle
- Reduced muscle strength

Functional Impact

- ↓ resistance to movement
- Loose muscles
- Less stable joints
- Poor balance
- Reduced total daily energy output
- Reduced fat burning potential
- Poor posture
- Hypoventilation
- Reduced respiratory fitness
- Reduced physical capacity
- Prone to daytime sleepiness
- Reduced motivation

Physical Features in PWS 2

Clinical Features

- Increased % body fat

Functional Impact

- Increased fat storage ability
- Gain fat readily
- Increased cardiac risk
- Sleep apnoea risk
- Reduced energy intake requirement

  dieting ➡ loss of muscle loss

  (if not exercising)

Physical Features in PWS 3

Clinical Features

- Hypothalamic ↑ hunger / ↓ satiety
- Reduced hormonal maturation
- Desire sameness

Functional Impact

- Constant food focus
- Hyperphagia
- ↑ risk of osteoporosis
- Dislike new interventions
- *Like consistency*
- *Regularity increases compliance*

The Benefits of Exercise

- Musclo-skeletal improvement
  - Muscle strength
  - Joint stability
  - Bone density
- Achieving motor milestones
- Weight management
- Cardio-respiratory fitness
- Vascular health
- Mood – endorphins / BDNF / cannabinoids
- Distraction from food focus

The Improvement of Obesity-related Co-morbidities

- Diabetes - ↑ insulin sensitivity
- Hypertension
- Circulation
- Hypoventilation / OSA
- Oedema / lymphodema
- Hypercholesterolaemia - ↑ HDL
  ↓ LDL
  ↓ Triglycerides

Exercise Picture

- Regular
- Aerobic & strengthening
- Low to moderate intensity
- Incorporated into daily routine
- One to one / group / fun / incidental
- **Not** an *optional extra*

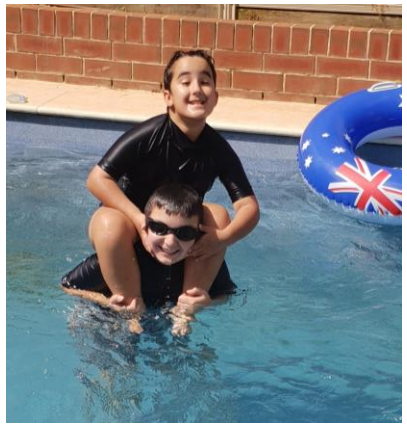
Where to Start

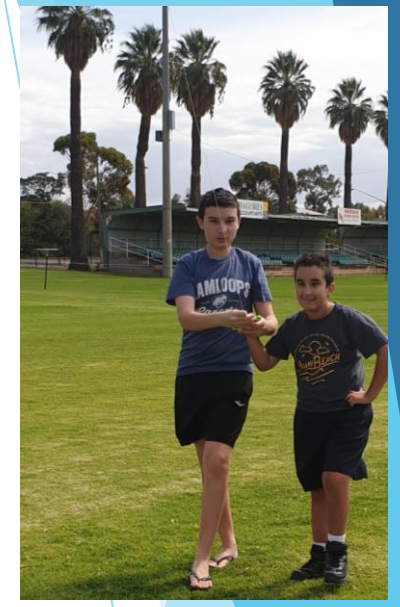
Childhood

- Sensorimotor stimulation
- Joint alignment
- Supported weight bearing
- Gross motor skills / coordination
- Achievement of motor milestones

- Physical Therapy
- Occupational Therapy
- Speech Therapy

Physical Fitness & Fun





Family and carer involvement

Part of Life

- **Adolescence / Adulthood**
  - Muscle strength & fitness
  - Physical capacity
  - Prevent or manage co-morbidities
  - Weight management
  - Bone density
  - Mood
  - Reduction of food focus and boredom

Effective Exercise 1

Aerobic

- 30-60 minutes
- 5-6 days per week
- Before a meal or snack
- Supported or supervised
- Examples - walking / treadmill
  - cycling / air walker
  - swimming / water exercise
  - dancing / video games
  - sport / play / outings

*** Include warmup & cool down*

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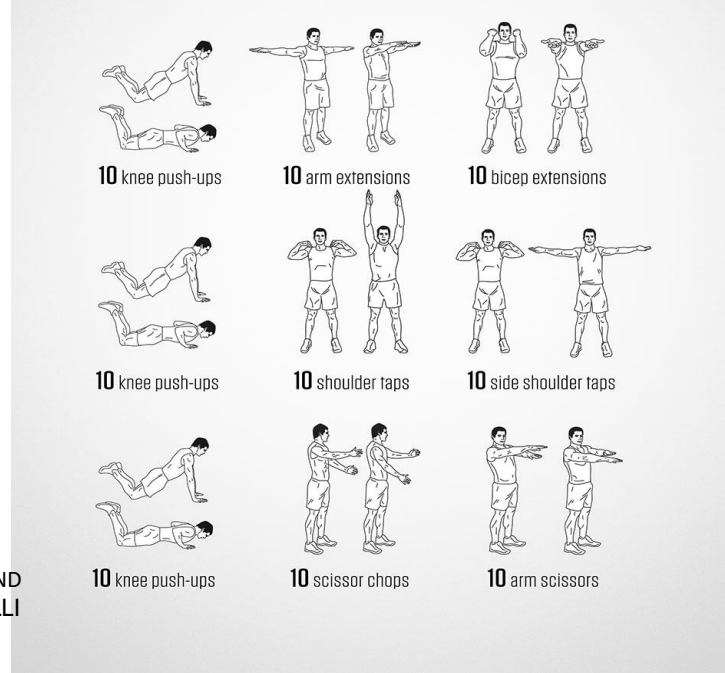
Effective Exercise 2

Strengthening

- Specific muscle groups
- Weighted/resisted arm exercises
- Upper body & trunk exercises
- Bush / sand / rock walking
- Ball play – throw/catch/bounce
- Up & down stairs
- Incidental activities - tidying room
  cleaning
  hanging out washing

- ** *Encourage good posture*



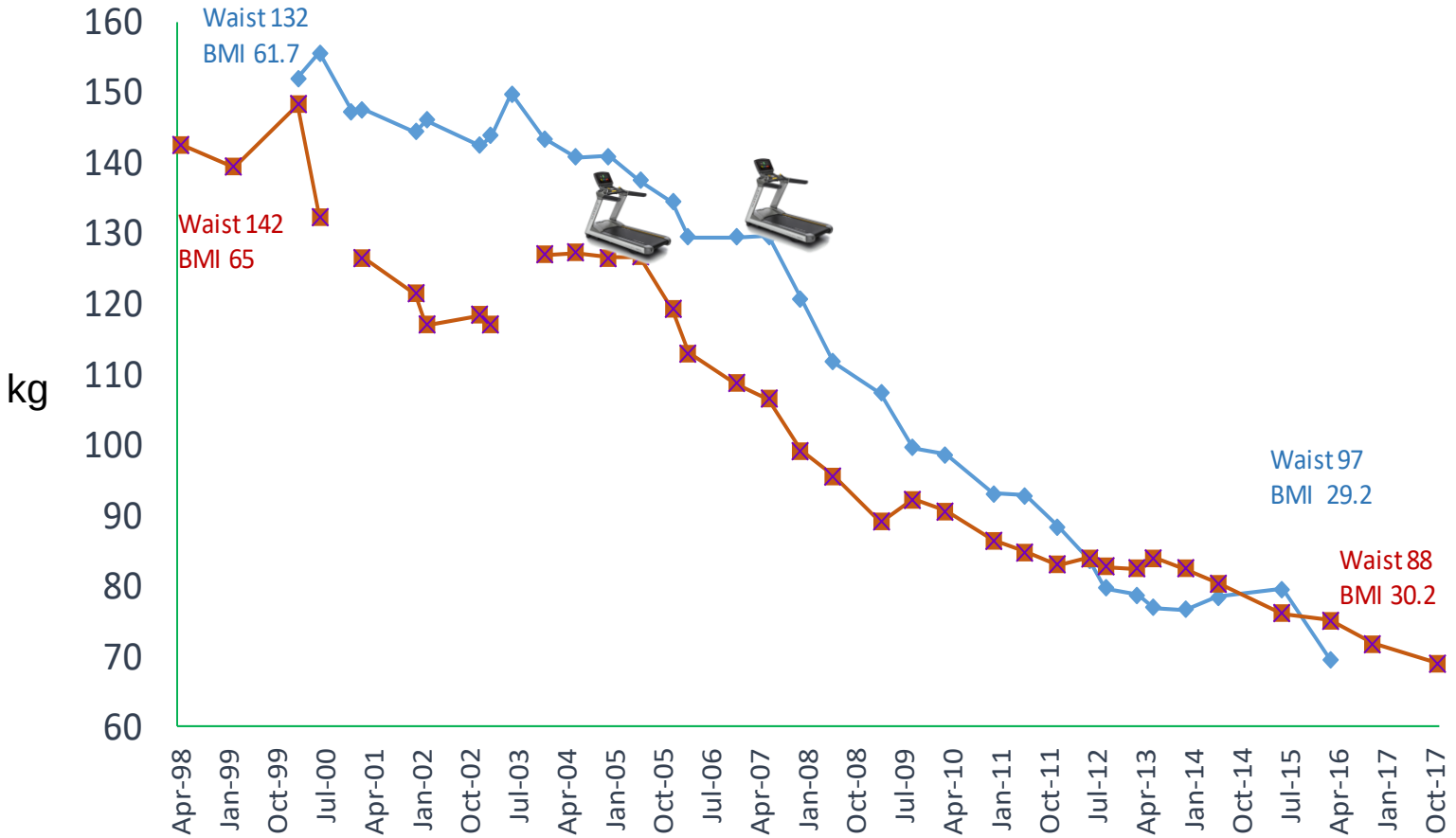
URS EIHOLZER, MD,YVES NORDMANN, MD, DAGMAR L'ALLEMAND, MD, MICHAEL SCHLUMPF, SILVIA SCHMID, PHD, AND KATRIN KROMEYER-HAUSCHILD, MD – IMPROVING BODY COMPOSITION AND PHYSICAL ACTIVITY IN PRADER-WILLI SYNDROME. *J. Pediatrics 2003 142:73-78*

Case Examples

SB(-79.5kg) & DB(-86.3kg)

"The measure of individual freedom *(in Prader-Willi syndrome)* correlates with body weight"

- Prof Andrea Prader



Waist (cm) BMI (kg/m^2)

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Maintained Fitness

August 2021

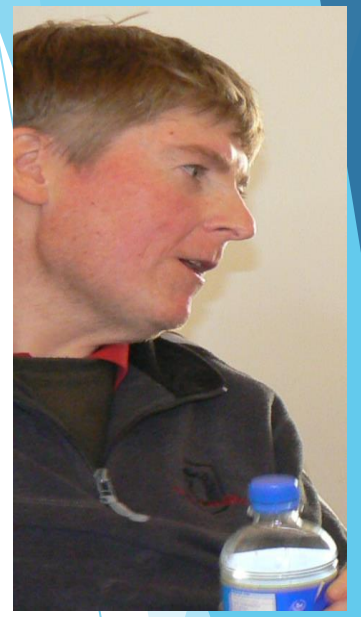
Age: 28 yrs

Weight: 72 kg

BMI: 23.5 kg/m2

Waist: 88 cm

Day	Activity	Duration
Monday	Maui Thai *or* Special Olympics swimming *or* Dog walking	60 mins 60 mins 60 mins
Tuesday	Gym- X trainer & weights	60 mins
Wednesday	Walk on treadmill at home	40 mins
Thursday	Gym *or* treadmill at home	45-60 mins
Friday	Dog walking, washing and feeding	90 mins
Saturday	Walks on treadmill at home	40 mins
Sunday	Gym - Tough Class	45 mins



exercise works...

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