

Physical health in PWS:

Caregivers' Forum

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Topics for questions sent for this meeting



WEIGHT AND
NUTRITION



HORMONES



MEDICATIONS AND
SIDE EFFECTS



GENERAL HEALTH



PHYSICAL HEALTH
MONITORING



EXERCISE

Weight, BMI and DEXA scan

Ideal weight in PWS:

When a person is healthy, can move and run easily, without joint and respiratory problems.

BMI: $\text{weight in kg} : \text{height} \times \text{height in m}^2$: normal: in general 18-25kg/m²

- ex : 70 kg and 160 cm: $70 \text{ kg} / 1,60 \times 1,60 \text{ m}^2 : 27 \text{ kg/m}^2$

People with PWS have small muscle mass in general, and more body fat than others.

- DEXA scan can show muscle: fat ratio. Often 20% more body fat than others with same weight

Example: woman 30 år, 145 cm, 81 kg,

- DEXA scan shows: amount of fat in her body: 45kg., is over 1/2 of her weight : BMI: 39m²
- High risk of Diabetes type 2, elevated blood pressure, and hypercholesterolæmi

Nutrition and calorie needs

Nutrition:

- Low fat diet. Normal healthy food. Vitamin D every day
- Be aware of chewing function, obstipation, avoid too high in fibers
- Eat at served meals only. Avoid or limit alcohol

Calorie needs: because of small muscles: lower than normal for same height

- Great variation depending of activity. Examples to start with:
- For stable weight: 8 kcal pr cm body height (ex 150 cm: 1200 kcal)
- For weight loss: 6 kcal pr cm body height) ex 150 cm :900 kcal)
- For weight gain: 10 kcal pr cm body height (ex 150 cm : 1500 kcal)

Exercise

Moving burns calories

When moving:

Muscles work and use calories.

Motivation can be difficult:

Especially for those who are overweight.
Sudden changes or spontaneous plans
are often not well received.

Making walking a part of the daily routine can help:

When walking you carry your own body weight.

Try to incorporate walking wherever possible:

Take the stairs, or park further away
to increase walking distance.

Ask the person with PWS for their own ideas when making plans.

Hormones in PWS

Because of hypothalamic dysfunction people with PWS can have:

- Growth hormone deficiency
- Men: Testosterone deficiency
- Women: Estrogen deficiency
- Lack of thyroid hormones: hypothyroidism
- Diabetes type I : lack of insulin
- Diabetes type II: insulin resistance evt also lack of insulin
- All types of hormonal deficiencies demand medical treatment

Medications and side effects

Medication can be needed for many indications:

- Hormonal deficiency incl. diabetes
- Infections
- Allergy
- Psychiatric diseases: psychoses and depression
- Anxiety

Behavioural problems are NOT an indication for medication

In general: Be aware of possible side effects of each medication

Always start with low doses, half of normal, because of small lean body mass, to avoid side effects.

Thereafter increase if needed.



MEDICAL CHECK LIST: PWS

Doctors visit every ½- 1 year

Write down your questions before the visit

Check:

- weight, height, and blood pressure.
- Lungs and heart and circulation, skin, edema?
- teeth, joints, back

Discuss:

- Medication?
- Is the diet okay? Vitamin D?
- Sexuality?
- Blood tests: checked annually: hormones, diabetes, vitamin D?
- Dietitian, physiotherapist, other specialists if needed

Medical check-up visits in the clinic

- Blood pressure
- Annual blood tests:
 - Thyroid hormone and blood count
 - Sex hormones
 - Vitamin D, calcium, and phosphate
 - Cholesterols: with overweight and psychiatric medication
 - HbA1c for blood sugar.
- Dietitian as needed,
- Physiotherapist if needed
- Eye doctor: every 2-3 years
- Hearing: every 5 years

