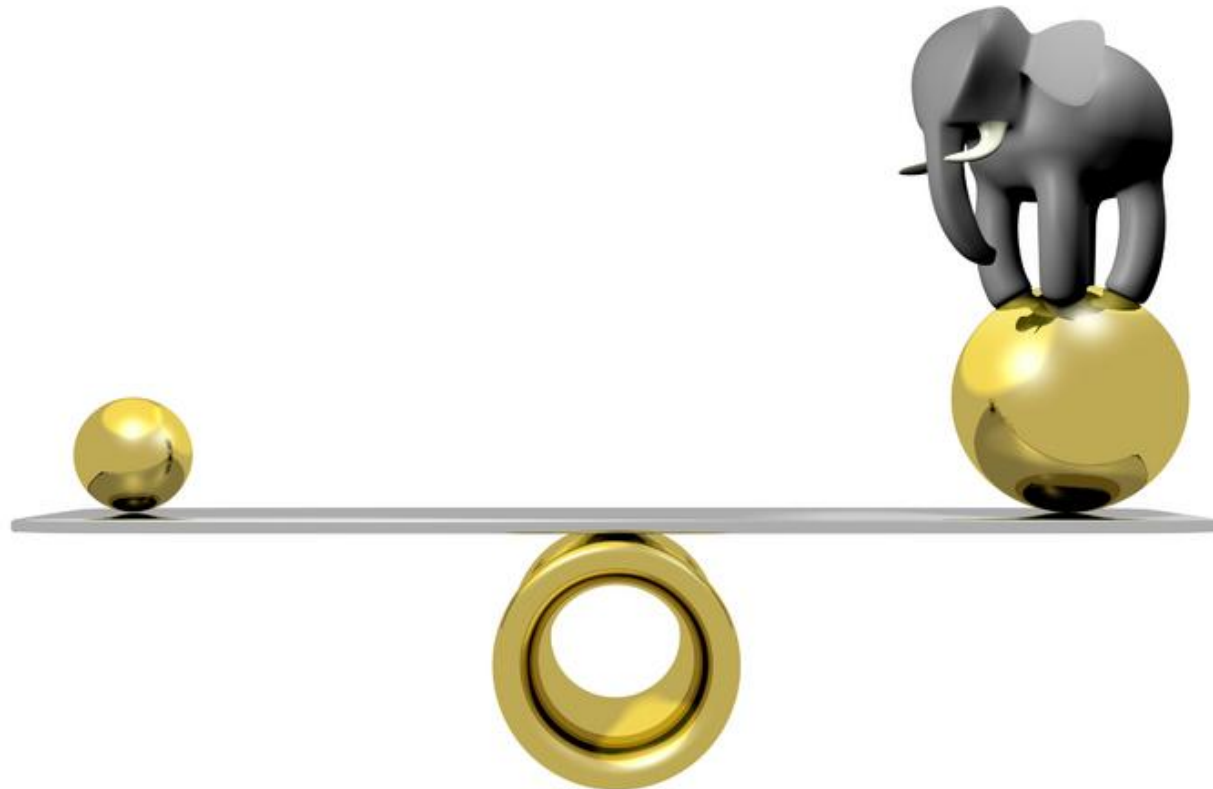


Keeping the Balance

Dietary needs for a person with Prader-Willi Syndrome



PWS is a “starvation syndrome”

- Because of the dysfunction in the hypothalamus, the brain tells the body it is starving; it must eat
- To a person with PWS, eating becomes the only means of survival
- Everything is directed towards this
- Knowing how to manage this is imperative

No choice



- There is no choice where food is concerned.
- It's as though there is no "on/off" switch
- It is critical to get the balance right

Having PWS means:

- Without support and good management, failure to thrive will lead to morbid obesity.
- From this...



To...this, in 21 years



Insatiable appetite means:



- No ability to control the urge to eat
- If not supervised, would eat continuously
- This will compromise health, and result in death
- This syndrome cannot be cured or changed by behavioural intervention
- Early Growth Hormone treatment can help with management

PWS needs strict guidelines



- A person with PWS (with or without GHT) can not be expected to make good food choices for themselves.
- They will try to convince you to break their dietary guidelines
- You must assist them in keeping to the guidelines

Caloric needs

- Without GHT, a person with PWS needs only one-third the amount of calories his or her peer would eat
- Make every calorie a 'working' calorie

One apple...



or
One teaspoon of oil?



Both have 44 calories each

Growth Hormone Treatment



- Being able to physically work off more calories will make a difference
- Set the goal weight for age and measure success by the scales

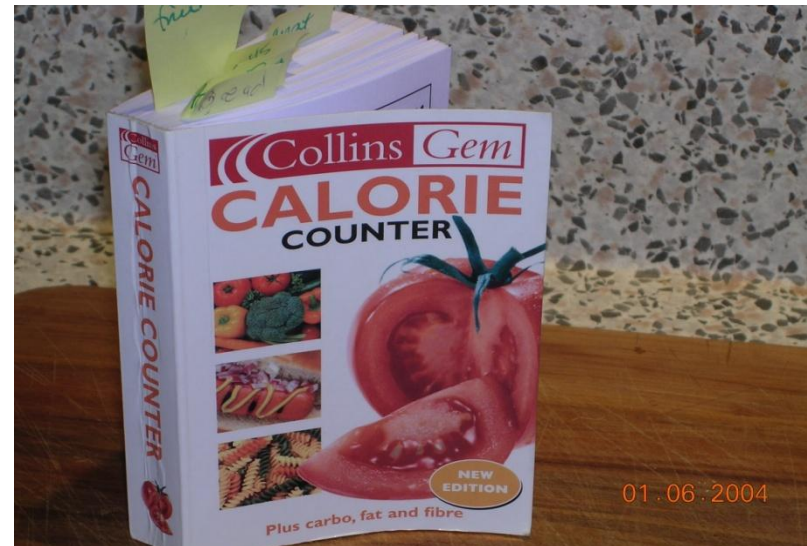
PWS without normal growth hormone

- The imbalance in PWS of having low growth hormone production means exercise will be harder for them
- Decreased quantity of muscle tissue accounts for the difference in energy expenditure
- With low muscle tone, it is harder to exercise



Counting Calories

- Counting Calories makes sense
- Keep in mind the 1,000 cal rule
- 300 cals per meal + snacks
- 1 calorie = 4.19 kilojoules



Keeping to the guidelines means menu planning

- Decide what calorie level the person needs
- Rule of thumb: 1,000 cals per day will help lose weight
- Work out balanced menus
- Count the calories
- Prepare ahead of time
- Always make sure what you say is on the menu is what they get
- If you deviate from the agreed caloric amount, the end result will be weight gain

Know exercises to burn calories

(for person weighing 90-99 kg)

- Swimming 30 minutes burns 360 cal
- Walking (5.6 km/hr) 246 cal
- Lawnmowing 318 cal
- Vacuuming 186 cal
- Dancing (easy aerobics) 282 cal

(for person weighing 80-89kg)

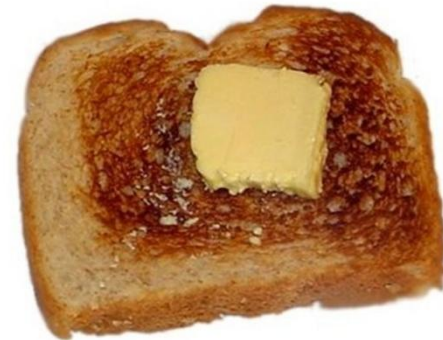
- Swimming 30 mins burns 324 cal
- Walking 234 cal
- Lawnmowing 285 cal
- Vacuuming 165 cal
- Dancing 249 cal

Calories in + calories out = weight loss or weight gain

● Breakfast	300 cal	● 30 min vacuum	186
● Snack	50 cal	● 30 min shopping	177
● Lunch	300 cal	● 30 min laundry	189
● Snack	50 cal	● 30 min walk	246
● Dinner	300 cal	● 30 min swim	360
		● 30 min walk	246
● Total	1,000 cal	● Total	1,404
		= weight loss	

Fat is the enemy

- Excess energy (ie food intake) NOT burned off as in exercise will be stored as FAT
- Fat is the hardest and the last food group to burn off. Humans are hard-wired to store fat against famine.



Know what calories look like



- Aussie Cheese Fries, with ranch dressing =
- 2,900 calories
- 182 grams fat
- This is a “starter” at the Outback Restaurant, USA

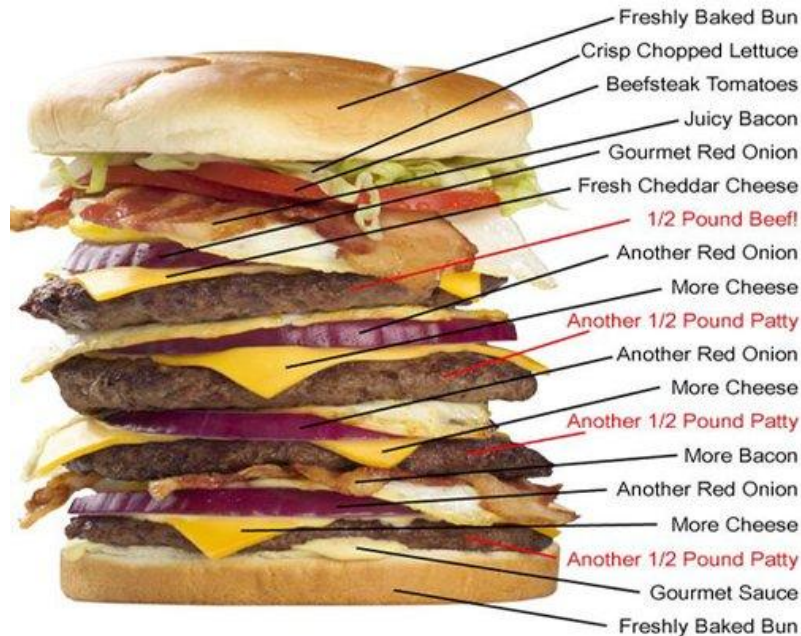
1 level tablespoon margarine = 5 grams

182 grams fat = 36 ½ level tabs margarine

Hamburger American style



Double double beef burger



- Beef 2,989 cals
- Bun 130 cals
- Cheese 84 cals
- Bacon 50 cals
- Mayo 148 cals
- Total 3,401 cals

BBQ

- 1 beef pattie 168 cals
- 1 sausage 405 cals

- Total cals: 732
- Total fat 141 grams
(Equal to eating 28 level tablespoons marg)



Fish & chips



- Average portion?
 - 600 cals
 - 56.6 g fat
- (Equal to 11 level tablespoons margarine)

Just one won't hurt?

- 480 calories in a banana nut cake
- 500 calories in one peanut-butter cookie
- 510 calories in a maple coffee cake muffin



Coffee at Starbucks, anyone?

- Starbucks coffee ranges from 380 – 750 calories
- With anything from 15 grams of fat
- (*is this really coffee 😊?*)



Small changes – big results

- Make three small changes a week – lose 200-250 cals from the daily intake
- Over the course of a year this will result in weight loss of over 11 kgs

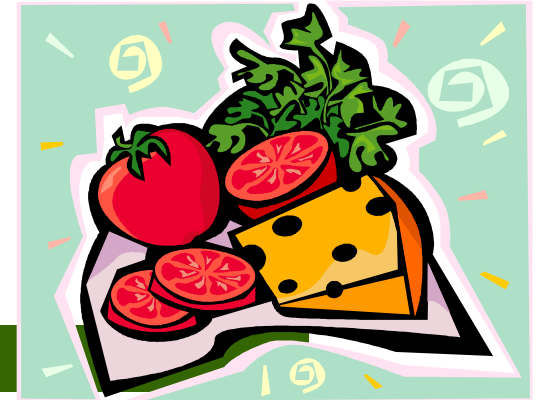


Being inventive

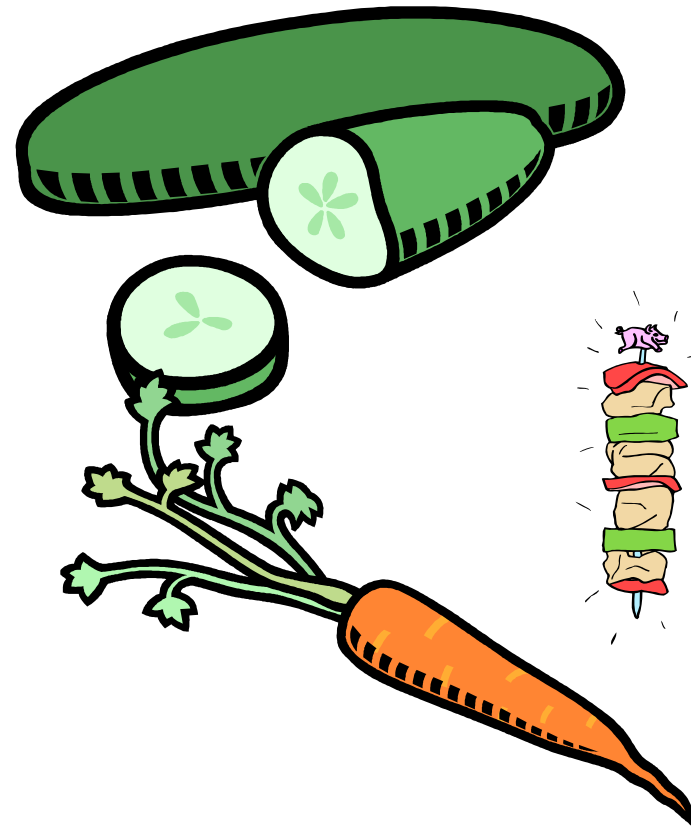
- Because 1,000 isn't very much, you must learn to be inventive
- Use smaller plates
- Plenty of small pieces look more than one large piece
- Use free foods to bulk up meal
- Be decorative with the food
- Consider putting all those with PWS together at one table



Snacks



- Sticks of raw vegetables
- Low-fat dips
- “Kebab” cubes of fruit and veg on sticks
- Freeze fruit pulp and water as iceblocks
- Weight-watchers low-fat snacks



Read Labels

- Check fat content – low fat can mean high sugar
- Check sugar content – low sugar can mean high in fat
- Remember each is as bad the other!
- “Lite” “98% fat free” are only comparative marketing ploys. Ask yourself, 98% fat free compared to what? 100% fat? No – only compared with the next product.
- The following slides are examples of label-reading



NUTRITION INFORMATION		
SERVINGS PER PACKAGE: 4		
SERVING SIZE: 62.5 g		
	AVE. QTY PER SERVING	AVE. QTY PER 100 g
ENERGY	107 kJ (26 Cal)	171 kJ (41 Cal)
PROTEIN	1.4 g	2.3 g
FAT - TOTAL	1.0 g	1.6 g
- SATURATED	0.3 g	0.5 g
CARBOHYDRATE - TOTAL	2.7 g	4.3 g
- SUGARS	LESS THAN 0.1 g	LESS THAN 0.1 g
SODIUM	225 mg	360 mg
INGREDIENTS		
CHICKEN STOCK (56%) (WATER, CHICKEN, HERB EXTRACTS), WATER, MODIFIED TAPIOCA STARCH (1442), WHEAT FLOUR, CHICKEN FAT (1.5%), CHICKEN (1%), SALT, VEGETABLE PROTEIN EXTRACT (CONTAINS SOY), YEAST EXTRACT (CONTAINS BARLEY), FLAVOURS (CONTAIN WHEAT, SOY AND MILK PRODUCTS), FLAVOUR ENHANCER (635), COLOURS (CARMEL III (CONTAINS WHEAT), BETA CAROTENE), GARLIC, SPICES.		

- Energy = calories
- To convert kilojoules to calories, divide by 4 (approx)
- Serving size (in sample) is 62.5g (1 tablespoon = 20g)
- Note difference between “ave qty per serve” and “ave qty per 100g”. Don’t confuse the two.
- **INGREDIENTS:** go in order of amount in package



PER 150g SERVING INFORMATION
(for 1 pack of noodles cooked in 500 ml boiling water)

Servings per pack: 5
Serving Size: 150 g (cooked noodles)


	AVERAGE QUANTITY PER SERVING	AVERAGE QUANTITY PER 100 g
ENERGY	866 kJ (208 Cal)	559 kJ (134 Cal)
PROTEIN	7.4 g	4.8 g
FAT - Total	0.9 g	0.6 g
- Saturated	LESS THAN 1 g	LESS THAN 1 g
CARBOHYDRATES - Total	41.5 g	26.8 g
- Sugars	1.9 g	1.2 g
SODIUM	465 mg	300 mg

INGREDIENTS
WHEAT FLOUR, WATER, ENRICHED EGG PULP (5%)

- These look good! “98% fat free” but look at the serving size:
- Serving size is 150g of cooked noodles
- 208 calories for one serve leaves only 92 calories for the rest of the meal
- 100g (134cal) still only leaves 166 cal for rest of the meal

Couscous

- Av serve is 100g, or 1500kj
- Convert to calories: divide by 4 = 375
- This is too much for a 300 cal meal.
- Reduce by $\frac{3}{4}$ to 25g = 94 cals leaving 206 cals for rest of meal



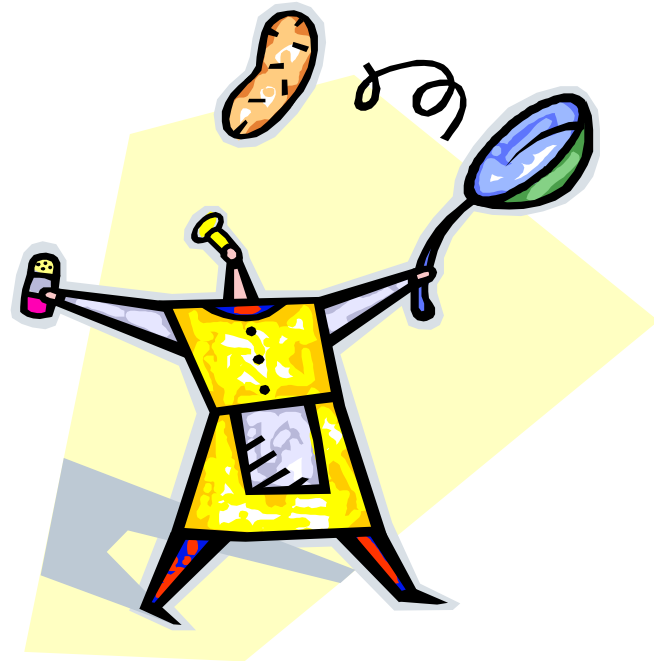
For more delicious recipes, visit www.sanremo.com.au

NUTRITION INFORMATION INFORMAZIONI NUTRIZIONALI INFORMACIÓN NUTRICIONAL NAHRWERTANGABEN INFORMATIONS NUTRITIONELLES 營養成分	AVERAGE QUANTITY/VALORI MEDI/CANTIDAD PROMEDIO/DURCHSCHNITTMENGE/ QUANTITÉ MOYENNE/ 平均份量	
	AV. QTY PER SERVE*	AV. QTY PER 100g*
Energy/Valore Energetico/Energia/Energie, Valeur Energetique/ 能量	1500kj	1500kj
Protein/Proteine/Proteinas/Eiweiß/ Proteine/ 蛋白質	11.5g	11.5g
Fat, total/Grassi/Grasas/Fett/Grasse/ 脂肪	1.5g	1.5g
- Saturated Fat/Grassi saturati/Grasas saturadas Gesättigte Fettsäure/Grasas saturées/ 飽和脂肪	0.6g	0.6g
Carbohydrates/Carboidrati/Glúcidos/ Kohlenhydrate/Glucide/ 碳水化合物	71.0g	71.0g
Sugars/Zuccheri/Azúcar/Zucker/Sucres/ 糖	1.5g	1.5g
Fibre/Fibra alimentaria/Fibras alimenticias/ Ballaststoffe/Fibre alimentaire/ 纖維	4.0g	4.0g
Sodium/Sodio/Sodio/Natrium/Sodium/ 鈉	100mg	100mg

*Refers to dry couscous

Change cooking methods

- Stirfry
- Grill
- Bake
- Microwave
- Steam
- Non-stick pans



Look for foods low in GI

- **GI = Glycemic Index**

Choosing low GI carbs can help you feel fuller for longer, increase energy levels, making weight loss achievable and sustainable

- Carbs low in GI lower insulin level, reduce risk of heart disease and diabetes, minimise body fat and increase energy levels

Alghouth low GI foods often contain more calories, these are real 'working' calories and better for you

- Eat 7 or more servings of fruit and vegetables daily
- Low GI breads & cereals, soybeans, chickpeas, lentils
- Eat nuts and seeds regularly
- Eat more fish & seafood
- Eat lean red meats, poultry and eggs
- Eat low fat dairy products

Examples of low GI foods

- Baked beans
- Butter beans (canned)
- Chick peas
- Natural museli
- Porridge
- Apple
- Banana

Decreased calories are good for everyone

- Low-fat milk, sugar substitute
- Too much fruit = too much sugar
- Eat more salads, raw vegetables
- Clear soups with pasta, rice, vegetables, tsp Vegemite
- Avoid butter altogether

Weight Loss programme

- Keep goals realistic
- Rule of thumb: 1-2 kg loss per month is fine
- Keep weight steady if still growing
- Little and often is better
- Drink plenty of fluids
- You be reasonable – they often can't!



Exercise often

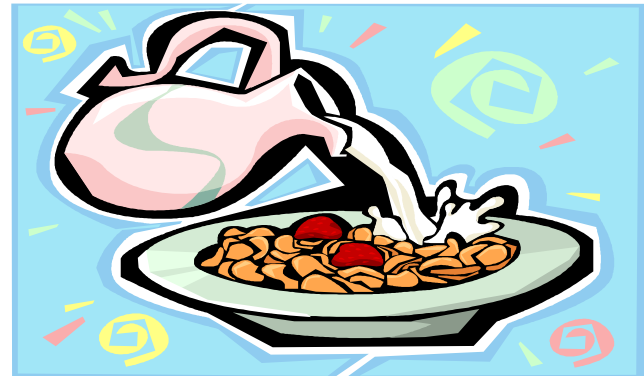
- Swimming
- Walking
- Horseback riding
- Gym
- Aqua aerobics
- Hiking
- Games
- Hidden exercise
 - Climbing stairs
 - Park further away
 - Hanging out washing
 - Housework!
 - Window-shopping
- Make it fun

Locks are a safety measure

- Keep all food places secure.
- Leaving unlocked cupboards will mean failure – they will be pilfered
- Locks are a safety measure
- The bottom line for freely available food for a person with PWS, is death.

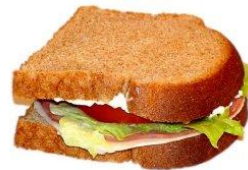
What does 1,000 cals look like?

- BREAKFAST (300cals)
- 1 cup (30g) low-fat cereal
- 1 small banana
- 1 glass milk



Lunch

- 1 sandwich (thin Vogels bread) spread with marmite, few chopped walnuts and coleslaw
- Coleslaw in pottle (small)
- 1 piece fruit
- 1 low-cal drink



Morning & afternoon tea

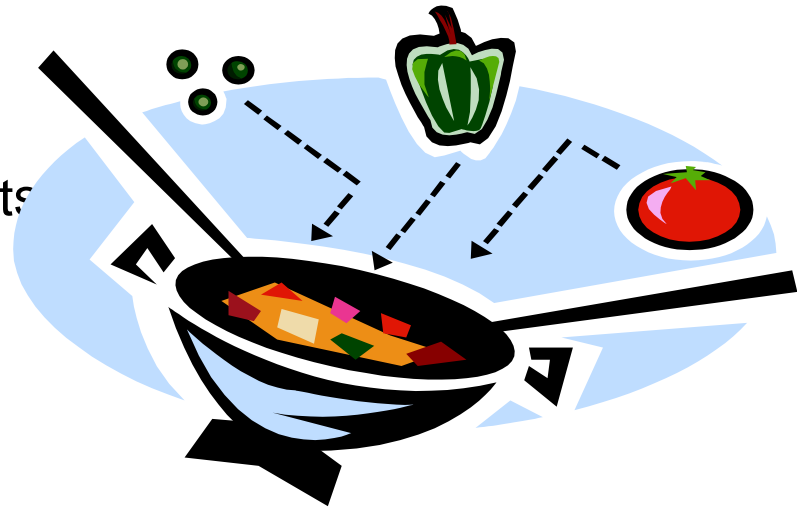
- 1 pottle low-fat yoghurt
- 1 low-fat muffin (50g) or fruit
- Platter of free foods:
gherkins, celery,
cucumber, sliced
tomatoes, peppers,
carrots or mushrooms
with low-fat dressing



Dinner

Chinese Chicken & beansprouts with walnuts

- 50g chicken stirfry with lemon, herbs, mushrooms, dash soy sauce, add handful beansprouts & sprinkle with 15g chopped walnuts
- 1 cup of seasonal vegetables
- Salad if desired
- Total for the day: 913 calories



Special Occasions

- Plan well in advance – plan with the person, working out a party menu that looks good, is healthy, and won't break the calorie bank!
- Check out Weightwatchers and other dietary plans
- If possible, increase exercise to help balance extra calorie intake



Remember...

- Accept that food dominates their lives
- Change everyone's eating habits – it can only be good for them!
- Stay away from processed foods
- Introduce whole and raw foods that take longer to digest
- Do NOT leave unsupervised around food
- Bulk up meal with “free” foods (salads, raw vegetables)
- Use smaller plates
- Make food attractive
- Clear away food after meal
- Stick to a routine
- Do not use food as a reward or punishment
- Do not set person up for failure

Never forget...

- The hand is quicker than the eye
- A lie saves face
- Unless you see chocolate around the face, it hasn't happened!
- Try to balance 'nicked' food with the diet
- Pick your battles...
- Age appropriate responses
- Don't set *yourself* up for failure