The following document was agreed by the PWSA Dietary Advice Forum (now operating as the Dietitians Network)

The Care Quality Commission (CQC) has the responsibility for ensuring that those providing care to people in a residential setting meet certain important standards. One of the standards requires that care providers:

‘Ensure personalised care by providing adequate nutrition, hydration and support.’ Outcome 5 (Regulation 14)

The objective of the standard is that:
(1) Where food and hydration are provided to service users as a component of the carrying on of the regulated activity, the registered person must ensure that service users are protected from the risks of inadequate nutrition and dehydration, by means of the provision of—
(a) a choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users’ needs;
(b) food and hydration that meet any reasonable requirements arising from a service user’s religious or cultural background; and
(c) support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
(2) For the purposes of this regulation, “food and hydration” includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed. Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010

Food and fluids are necessary for everyone to provide the nutrients essential to keep the body healthy and to promote growth or healing where appropriate. In addition, suitable food and nutrition is vitally important for people with Prader Willi Syndrome (PWS) to achieve and maintain an appropriate weight for health.

This document is intended to guide care providers as to the best ways to achieve the standard.

Menus

Menus should be devised in consultation with the residents to ensure that there is sufficient choice and that they take account of an individual’s likes and dislikes. The menus should be well balanced and appropriate to the needs of the residents. This will generally require menus to be low calorie, low fat, low sugar and low salt. Meals should be presented in an attractive and appetising way and care should be taken to maximise the look of the meal. This will be best achieved by incorporating plenty of fresh vegetables, salad and fruit into the menus.

The member(s) of staff responsible for devising the menus should have appropriate training e.g. the level two award in healthier food and specialist diets awarded by the chartered institute of environmental health. All menus should be checked by the dietician who is aware of the specific needs of the residents. If this is not possible through the local hospital, further advice may be sought from the Prader Willi Syndrome Association UK.
Residents should be encouraged to discuss the menus and give their comments. An annual questionnaire is a valuable method of seeking such feedback and, where a resident is unable to complete this questionnaire, they should be helped to do so by an independent party. Menus and mealtimes should be a regular agenda item at staff meetings.

**Meal times**

Mealtimes should be flexible and not rushed. Aids and adaptations should be provided if needed. If the resident requires assistance with eating and drinking, this should be clearly documented in the care plan and support documentation. Assistance or adaptations should be provided in a discrete way and the residents privacy and dignity should always be respected. If a resident wishes to eat alone, this should be allowed if possible and should be fully risk assessed.

Due to the poor muscle tone of an individual with PWS and the risk of choking, meal times must be discretely supervised. If required a referral should be made to the speech and language department for support and guidance. If a resident wishes to eat alone, this is allowed as much as possible and is fully risk assessed.

**Food outside the home**

People with PWS should be able to participate in community life around them. This will often include occasions that involve food. They should be supported at all times to achieve this in a low risk way.

The expected nature of all occasions should be determined in advance. The availability of food and drink should be discussed with the person with PWS in a positive manner. Agreement should be reached before the event about what food and drink they will be able to have. On special occasions extra treats should be allowed if agreed beforehand. If appropriate, adjustment should be made to prior intake to compensate. In a similar way, plans should be made for managing food over the holidays.

**Choice**

Mealtimes and menus should be a standing agenda item for residents’ meetings and feedback received should be recorded and acted on where appropriate. It should be taken into account when new menus are planned. Residents should also be able to speak directly to the cook (if applicable) and discuss alternatives should they not want what is on the menu. Individual food preferences should documented in the resident’s care plan and support file. A list of their likes and dislikes may also be kept in the kitchen.

Due to the problems of appetite control common in PWS, snacks cannot be freely available, however, low energy foods such as vegetables, fruit and low energy drinks should be available through the day.

**Independence**

Some degree of self regulation in a PWS dedicated facility does not mean that this will be successful in a general residential home. No other medical condition requires the long term, extremely low energy intake generally required of persons with PWS. Some adults maintain their weight on 1000 calories per day (4.2MJ) or less, even with an exercise program.

If they are to participate in decisions about their meals, people with PWS may need more information about their own disorder and about their diet. Staff should be able to provide this or to direct the resident towards a reliable source of information. Staff should listen to their concerns about food, and their special food preferences should be taken in consideration when the food is prepared.
Support should be put into place to promote as much independence as possible at meal times. Where appropriate, residents should be encouraged to participate in food preparation, making drinks, setting the table etc. Risk assessments should be completed. However, they may require a lot of reassurance, they need to be aware of, and included in, decisions that affect them, they need to know that their needs will be met. There should be good communication and agreement between staff and family. Whilst control of food in this way might generally be considered an infringement of civil rights, for those with PWS it allows them to feel safe about the food.

**Weight management**

As people with PWS may gain weight very quickly it is beneficial that they are weighed on a weekly basis. For this to be achieved in an effective and dignified fashion it is important that:

- Accurate scales are available that are safe to use. These should be checked for accuracy on at least an annual basis.
- Staff should be trained in the proper use of scales.
- An accurate height should also be available. This may be carried out by the care provider if they have accurate stadiometer and appropriately trained staff. If this is not the case, a height measurement should be requested from the GP, local hospital or dietitian.
- Weighing should take place in a private space and with the full agreement and co-operation of the service user.
- Weights, once taken, should be recorded accurately in the person’s record. This record is confidential and should be kept in a secure place.
- Weights should be reviewed regularly to determine trends and magnitudes of change. This may be weekly or monthly depending on the needs of the individual. Weight does fluctuate from day to day and decisions should not be based on just two weight readings but on trends over three or more readings.

All residents should discuss with their GP their ideal target weight and the GP should support the staff in achieving this. A referral to a dietitian should be sought if the GP is not well informed about PWS (many GPs will never have encountered PWS or will have seen only one or two patients with the condition). The GP or dietitian should be encouraged to seek advice from the Prader Willi Syndrome Association (UK) if their experience of the condition is limited.

Where a weight loss program or other special dietary regimen is required, details of this should be documented in the person’s care plan. The diet regime should be determined for the individual depending on their needs, which can vary considerably.

The following is a guide and further advice may be sought from the dietitian or the PWSA UK:

- If weight loss is required, 7-9 kcal/cm height is a reasonable starting point.
- If stable weight is wanted, start with 9-10 kcal/cm height, e.g. 1500 kcal/day for a person of 150 cm.

The regimen should be adjusted in response to changes in weight over subsequent weeks.

Even with a low body mass index (BMI)*, adults with PWS may have a higher percentage of body fat than typical. Examination of body composition, together with BMI, is useful when estimating the nutritional needs for a person with PWS. A person with PWS needs a lifelong diet that is adjusted based upon body composition, BMI and daily activity. Families and staff must have detailed information about food items, daily management of food etc.
Food should be distributed evenly through the day. For example, an overweight adult on a diet of 1,000 calories per day should receive 3 meals of around 300 calories per meal, with 100 calories left over for snacks. Low energy foods such as vegetables, low energy fruit and diet drinks should be included freely.

Where weight loss is required, consultation with a dietician and close follow-up are usually necessary, and locking of the kitchen, refrigerator, and/or cupboards is often essential. Assessment of adequacy of vitamin and mineral intake should be made by a dietician and appropriate supplementation prescribed as indicated. Calcium and vitamin D may be at particular risk.

From a medical point of view:
- The person is at a greater health risk if significant weight gain is not prevented or treated.
- Weight loss, if too rapid, can be dangerous for the body.
- Fluctuation of weight is a health risk.

The person with PWS might feel guilty if their weight goes up. There will be occasions when weight gain may occur. This needs to be handled sympathetically.

*BMI = \frac{\text{weight in kg}}{\text{height in metres}^2}\
BMI charts are available

General

All residents should have support plans and risk assessments for PWS and food related issues. Nutritional screening assessments should be completed for each resident and should be reviewed on a regular basis as appropriate for the individual, as documented in their care plan. Food and fluid intake charts should be utilised where a resident’s nutritional or fluid intake is of concern. The resident’s BMI should be monitored and documented in the support plan. External support from the dietician should be sought if there are concerns regarding nutritional needs. Advice and support can also be sought from the Prader Willi Syndrome Association UK.

All staff should undertake food hygiene training. All staff should have training in basic nutrition sufficient to allow them to understand the concept of a balanced diet. Evidence of all training should be available on individual training files.

Rigorous kitchen records should be kept for both food preparation and cleaning schedules. Clear policies should exist on nutrition, food hygiene, food safety, menu planning methodology, health promotion and health support. These should be reviewed regularly and should exhibit a review date.

Further sources of information

- **Information for Dietitians**
- **Dietary Management and Exercise – Information for Families**
- **Healthy Eating with Prader-Willi Syndrome – purchasable publication**