

# Starting nursery A-Z

Nursery is important for any child; it helps their emotional, social and personal growth. However, being able to put your trust in other people to take over PKU management for a few hours each day is a considerable hurdle. Consultant Dietitian, Professor Anita MacDonald provides some top tips for parents starting the nursery journey.

**A** Spending time identifying a suitable nursery is essential. Visit different nurseries, identifying ones with good staffing to child ratios. Read the nursery 'Ofsted' inspection reports. Nursery teams should demonstrate a positive attitude to the inclusion of children on special diets. A 'can do' attitude is important with particular emphasis on keeping each child in their care safe.

**B** Meet with the nursery manager, key worker, nursery cook and other relevant team members in advance of your child starting nursery. It may take more than one meeting to give all the information that you need. Ask your dietitians to visit the nursery with you.

**C** Every child in nursery should have a care plan. This should explain what PKU is and outline everything that should be done for your child in nursery e.g. administration of protein substitute, information about the low phenylalanine diet, action that should be taken if your child refuses their phenylalanine exchanges or vomits their protein substitute. The care plan is usually written by the nursery team, but with guidance from parents and health professionals. It is worthwhile spending time on this task ensuring the care plan matches all your child's needs. The more written guidance the nursery team have, the less likely mistakes in management will occur. Ask your dietitian to check the care plan. You should always have the final word in your child's care plan and you will need to sign this to confirm your agreement.

**D** Review the care plan at regular intervals, particularly if there is a change in protein substitute dose or type or number of phenylalanine exchanges

allocated per meal. Ask for formal review dates to be included in the care plan. Also ask to be informed if your child's key nursery worker changes - new team workers will also require training.

**E** Give your nursery a list of suitable foods, exchange foods and foods not allowed in your child's diet. Your dietitian will provide this information.

**F** It is good for young children to enjoy mealtimes with other children. Ask your dietitian to adapt nursery menus so they are suitable for a low phenylalanine diet. It is important to try and encourage your child to eat new foods in nursery. Sometimes they will eat foods for their key worker that they will refuse to eat at home. Request that meal

choices given to your child match what is given to other children. The nursery cook should be provided with suitable recipes - your dietitian can help.

**G** Agree with the nursery any 'regular' low protein foods that they can supply e.g. Violife cheese, Quorn Fishless Fingers, Rowntrees Jelly Pots (not sugar free), or Swedish Glace Ice Cream.

**H** Also agree with the nursery what you will supply e.g. low protein milk, protein substitutes, low protein flour, low protein bread or pasta.

**I** Check that the food portion sizes offered are not too large, and your child is not overwhelmed by the amount of food offered.

**J** Agree with your nursery team that they will supervise every meal, snack and drink that is given to your child. It is all too easy for a child to help themselves to food on another plate or they pick up another child's milk container.

**K** Ask the nursery team to keep a written record of everything that is eaten and uneaten. They should return this record to you each day. Alternatively, they could photograph food plates at the beginning and end of each meal so you can see exactly what has been offered. This task may take a few seconds longer, but it is worth it for 'piece of mind'.

**L** Encourage the nursery team to use a different coloured food mat, plate or dish so nursery workers can easily identify your child.

**M** Also ask the nursery to use a different coloured cup or beaker. If your child drinks low protein milk rather than water in school, ask that this is given at the start of 'drink time' so the nursery team remember to give the correct drink. Alternatively, they need a system to check the correct 'milk' is always given.

**N** Agree an emergency plan if your child eats something they should not eat. The school should advise you immediately if this happens, so you can adapt the remaining days meals appropriately. Advise the nursery that whilst this would not cause immediate severe reactions, repeated dietary errors will increase blood phenylalanine levels, and negatively affect behaviour, lower child mood, their concentration, ability to learn and ultimately lower IQ.

**O** Talk to the cook and your child's key worker weekly about menus and food intake so you can discuss any mutual concerns.

**P** Ensure the nursery have working electronic scales to measure protein exchanges and protein substitute powder if necessary.

#### Taking the protein substitute at nursery

**Q** If your child is in nursery for over three hours each day, it will be necessary for the nursery team to administer the protein substitute.

**R** Explain the purpose and importance of protein substitute, when it should be given and how it is given. Show them what it looks like and how it is prepared. If it is a powder, you may agree to weigh this out each day and send in a sealed pot, so the nursery team just add water and mix prior to administration. Alternatively, you may supply a box of protein substitute sachets or pouches as necessary. Ask that (as far as practicable) only a limited number of the nursery workers take responsibility for protein substitute administration. Explain that consistency of protein substitute administration is essential.

**S** Signed records should be kept, demonstrating that protein substitute has been given. Ask for 'unwashed' protein substitute pots or pouches to be returned home each day so you can check if any protein substitute is remaining.

**T** If your child refuses or vomits the protein substitute, ask the nursery team to contact you for advice.

#### Other top tips

**U** Nurseries may provide children with fruit and vegetables such as mange tout (60g = 1 exchange) for mid-morning snacks. Advise that all fruits (except figs and passion fruit) are exchange free and encourage the use of exchange free fruits and veg at snack time.

**V** Check if the nursery does any activities that involves food e.g. cinema afternoon and popcorn, forest school and hot chocolate drinks, Easter egg making, disco afternoon with cookies or even nursery graduation with celebration cakes. Ask the nursery to give you advanced notice of any activities so you can provide appropriate ingredients or food alternatives so that your child is not excluded from any activities.

**W** Provide the school with a container of treats e.g. lollies or small packs of suitable sweets. Sometimes nurseries allow parents to provide 'sweet' treats for a child's birthday; if the nursery keeps a stock of suitable treats your child should not miss out.

**X** Inform the nursery about aspartame, particularly in drinks and foods like sugar free jelly pots. Most nurseries have a water or 'milk' policy for drinks, but they may give squash drinks for special occasions. Ask to check the ingredient labels on any squashes that they may keep in their cupboards.

**Y** It is also a good idea to give the nursery a list of suitable ice lollies. They may give lollies in the summer to help keep the children cool. There is an updated 'picture' book of suitable lollies on the NSPKU website.

**Z** Messy play is a common activity in many nurseries, and this may involve the use of play dough. It should be unnecessary to make special play dough from low protein flour, but if a child did inadvertently eat a small amount of play dough, please ask the nursery to inform you, and seek advice from your dietitian if necessary.