

**Parents Guide for
Starting School
by NCIMD psychology**



Starting school with a low protein diet



Starting 'big' school is an exciting time for you and your child. Moving from pre-school to primary school is a big change in any family's life, so it's normal to feel a little nervous. This move can feel a little scarier if your child has a metabolic condition.

However, there is no reason why your child won't settle into school life. With good communication and preparation, your child can get the right nutrition, and their blood levels can also stay well within range. In fact, the routine of school can help with this!



Before starting school

It is important to explain that your child has a metabolic condition to school staff. Remember that teachers are looking forward to welcoming your child into Junior Infants. Sharing information about your child's condition will just help teachers to support your child's needs.

Meeting with your child's teacher to explain the condition and the need for a low protein diet may be helpful. Your child may need to take their synthetic drinks/medication in school or you may need help in checking what your child has eaten or left uneaten, so it is important that teachers have an understanding of your child's needs. You may also need to discuss what teachers should do if your child becomes unwell. See Metabolic.ie for useful downloadable letters that can be shared with teachers to improve their understanding of protein-related metabolic conditions.



Preparing your child for the transition

It is completely normal for your child to have mixed feelings about starting 'big school'. They may feel a little sad when they leave their preschool, friends and teachers. They might also worry about going to a bigger school. Moving to a new place means getting used to a new building, meeting new people, adjusting to new routines, following new rules. They may also have worries related to their metabolic condition. Talking to your child about their feelings will help them to be better able to understand and cope with the changes, and regulate their feelings.



What is emotional regulation?



Emotional regulation is being able to understand and manage our own emotions in a healthy way. As parents, it's important for us to support and guide our children in developing these skills. Emotional regulation means that children can recognise and understand their feelings, like being happy, sad, or angry, and learn how to cope effectively, without dismissing emotions, or using distraction too much. As parents, we can support our children's emotional regulation by providing a safe and nurturing environment. This includes helping them label and understand their emotions, listening to their feelings without judgment, and teaching them coping strategies like deep breathing, calm cuddles, taking breaks, or talking about their feelings.



Why are emotional regulation skills important?

Being able to understand and manage feelings (regulate emotions) contributes to better academic performance in school, social skills, as well as mental and physical health later in life.

Emotional regulation includes.....



How a child expresses their feelings



Which things they will focus on



How they view a situation



How they will respond to a situation

How do I support my child?

1. Notice your child's feelings and name them as much as possible
"I think that you're feeling...happy, sad, angry, disappointed, frustrated, excited..." This teaches children how to recognise and label their own emotions

2. Name your own feelings as you are feeling them - "I am feeling ... happy, sad, angry, disappointed, frustrated, excited..." This teaches children how to recognise emotions in others

3. Match your feelings, and your child's feelings, to skillful behaviour- "I can see you're feeling angry, let's take a big breath and count to ten".

Or for some children, this might make them more mad! So you can say "I can see you're angry. Let's do jumping jacks to let the angry energy out!" "I can see you're feeling sad, would you like a hug?" "I think you're feeling worried, do you want to tell me what's on your mind?" "I'm feeling tired, I'm going to get a drink of water" "I'm singing because I'm feeling happy."

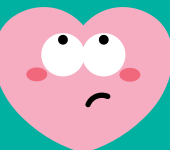




4. Ask your child how they are feeling and make time to talk about difficult feelings – worries or fears, being angry or sad. Let your child know it is ok to have these feelings. By learning to tolerate and talk about difficult feelings, children are less likely to react destructively to them. They learn that feelings are normal, and they are safe.



5. Remember that children don't always know, or can't always say why they feel a certain way. If they say "I don't know" when you ask how they're feeling, you can do two things and see which seems to help better. Firstly, you can make suggestions about why they feel how they do: "I think if I was you, I would feel tired because it's been a long busy day at school". "I think if I was you, I'd feel sad, because I'm miss my friends". "Does that sound right?" Secondly, you can say "that's ok, sometimes we don't know why we feel a certain way, would you like a hug/cuddle/ hot water bottle/blanket/warm drink?"



6. Remember that children at the age of starting school will often not be able to regulate themselves yet. They usually need an adult to co-regulate with, and to model for them and with them how to regulate themselves.

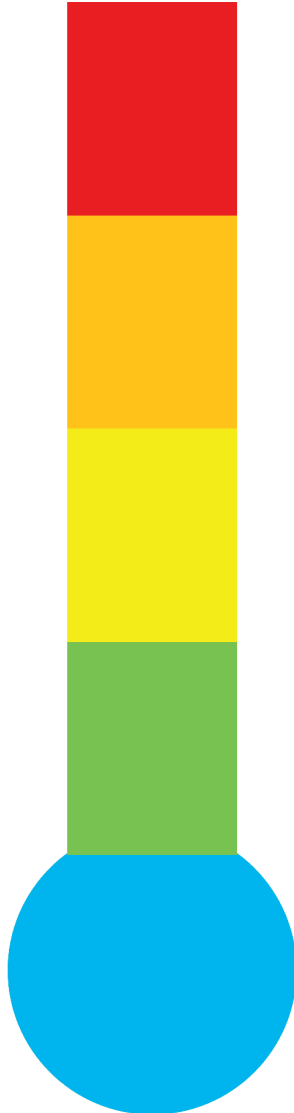


7. Practice naming feelings with Mood Cards or using a "Feelings Thermometer". Emotional regulation is a skill that takes practice – and the more we practice the better we get. Remember – you are your child's Emotion Coach!



Feelings Thermometer

How are you feeling?



Strategies for Supporting Your Child with Worry

1. Listen to the worry
2. Remain calm and empathetic
3. Let your child know it's quite normal to have worries and that it can feel uncomfortable, but that they are safe
4. Help your child to externalize worry and talk back to it (see worry monster below)
5. Once a worry has been listened to and a plan made then it is important to move on.
6. Let children feel a worry and LET IT GO!



A worry monster in practice

This is the Worry Monster. He gets joy from picking on children and making them worried and scared. The more you talk about the Worry Monster and gang up on him with your allies, the weaker he will get and the sooner he will go away

Ask lots of questions about 'the Worry Monster'

"What is it making you do?"

"What is the worry saying to you?"

"How is it making you feel?"

"That sounds like the Worry Monster talking, what do you want to say back?"

Be clear that you are no longer going to give worry what it wants or fall for its tricks!!!



Different ways kids can talk to their worry monster

"You usually show up at these times so I am not surprised by you"

"I know you're just trying to help..."



"Not now, worry, but I'll get back to you on that..."

"You're not helping me, so I am going to ignore you.."





What is your worry monster called?

Establishing Routines

Try to maintain healthy routines and schedules to help your child feel more secure and reassured.

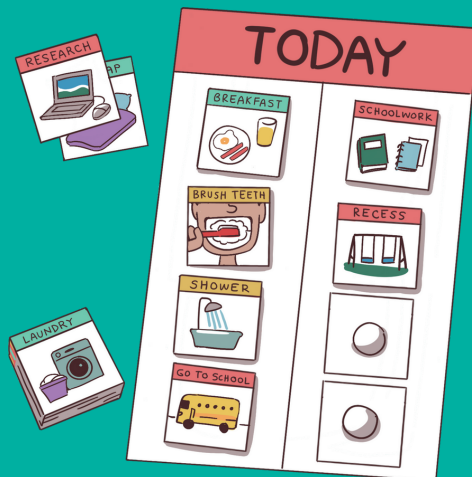


Establishing morning and evening routines at least 2 weeks before school begins.

Gradually adjusting your child's bedtime earlier over those 2 weeks to ensure they are well-rested for school.

Setting a regular bedtime routine, allowing for a calm 30 minutes before bed with no screen time.

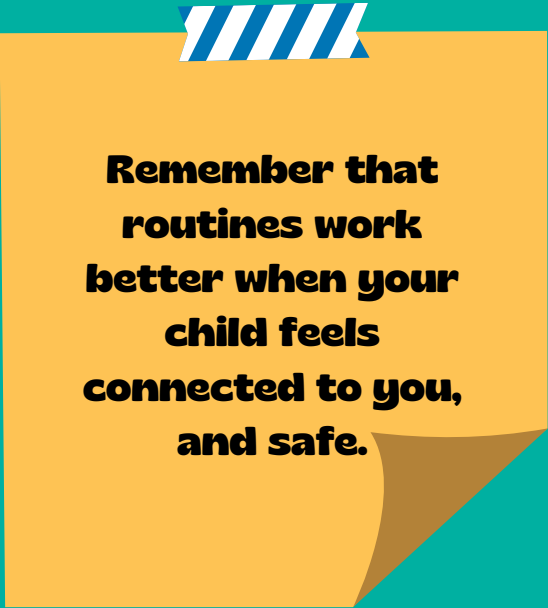
Following a consistent sequence of steps like bath, teeth brushing, putting on pyjamas, reading a story, and going to bed.



Practicing the morning routine of waking up early, having breakfast, getting dressed in the school uniform, and packing the school bag.

Making up songs for routine and transitions – songs really help children to remember routines and make them seem more playful! (The songs don't have to be any good..!)

Preparing everything the night before to minimize stress and avoid rushing in the morning.



Remember that routines work better when your child feels connected to you, and safe.



Promoting independence

Foster independence by allowing them to pack their own school bag, dress themselves, handle their lunch box and drink bottle, use the toilet, wash hands, and use tissues.

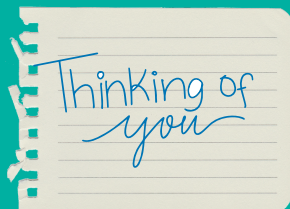
However, most children will need to build these skills gradually over time. Start with one or two skills, and once they have mastered this, add another skill in!

Remind your child about important tasks such as handwashing and coughing/sneezing into their elbow. Use stories or visuals to aid children in grasping new routines.



Transition

Provide a comforting object from home, such as a photograph or personal item, to help the child feel secure during the initial days and weeks of school.



Include a note in their lunchbox as a symbolic connection between you and your child, offering reassurance and reminding them that you are thinking of them.

Arrange opportunities for your child to spend time away from you with available childcare, gradually acclimating them to separation and subsequent reunions.

Use positive statements like "You'll have fun while I'm away, and I'm excited to play together when I'm back" to alleviate any anxiety and create a sense of anticipation.



Managing condition in school

Prepare your child to follow a low protein diet at school.



When and where to take protein supplements



Certain foods should be avoided



Food shouldn't be shared with friends



Leave uneaten foods/drinks in lunch box



Protein supplements keep us happy and healthy

Helping your child to explain their condition with peers

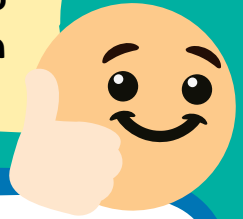
It may be helpful for your child's friends to know about their metabolic condition so that they can be supportive at lunchtime. You can talk to your child about ways to make new friends and how to explain their condition.

You can give your child a simple way to explain their condition that works for your family. This could be something like:

“When we eat food, our bodies break down the food into little parts that our bodies use to grow, and for energy. My body can't break some foods into little parts. The kind of food my body can't break into pieces is called protein. I can't eat meat/fish/dairy and some other foods because they have protein in them. If I eat these foods, it makes it hard for me to think and play, so I don't eat those foods. But our bodies need protein to grow, so I also drink a special drink that gives me the parts of protein that I need, in a way that my body can break down. This also helps me think and play!”



It is helpful for a child starting school to understand their condition so that they can talk to adults and peers about it. This way they are empowered to turn down food they are offered that it is better for them not to have. Although the suggested explanation is simple, it might take a child a few times to be able to remember the information and say it. You can practice this at home by teaching it to your child step-by-step, and by practicing with other children or family members.



It can also be helpful to talk to children about green, orange, and red foods (once they know their colours!).

This can simplify things, and take away the need to say “You’re not allowed that”.

You can say:

“oh, that’s a red food. Your body can’t break that down. I’m sorry, I know it’s hard not to have a food you want to try”.

Or

“Yes, that’s a green food! It is a food that you can eat, and will help you grow strong!”



You can also model that there are lots of foods that don't suit lots of people:

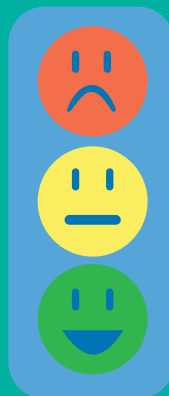
"oh cucumbers are a red food for me – my body doesn't know how to break it down, so it gives me an upset tummy".

Or

"Your cousin Jim has diabetes, so sugar is a red food for him, because his body can't use sugar for energy the way most people do."

Or

(with the neighbour's permission!) "Our neighbour Joan has a thing called high cholesterol. So she tries to make sure she doesn't eat a lot of foods with a lot of cholesterol in them. Those foods are red foods for her. "



What to expect when your child starts school

Children with PKU whose phe levels are higher than the metabolic team recommend may experience some symptoms:

- ♥ Tiredness
- ♥ Difficulty concentrating
- ♥ Increased activity; being very energetic
- ♥ Challenging behaviour
- ♥ Big emotions!

However, it's important for you to know that the above "symptoms" can also happen when any child starts school, because it is such a big, and sometimes overstimulating/overwhelming change for them!



So remember to keep an eye on your child's levels, and if they are high, you can discuss what has happened with the metabolic unit dietitians, and make a plan.

Remember to expect your child to be tired, and to need some "downtime" after the first few days and weeks of school! Even if they don't know/think they need it, they probably do!



Resources

Starting School with PKU

<https://lowproteinconnect.com.au/starting-school-with-pku/>

Starting school

<https://www.nutricia.ie/patients-carers/articles-stories/starting-school.html>

Getting Ready for Big School

<https://www.vitafriendspku.co.uk/pku-journey/children/living-with-pku/getting-ready-for-big-school>

Guidance for Parents of children transitioning from Pre-school to Primary School

<https://www.gov.ie/en/collection/84e52e-national-educational-psychological-service-neps-guidelines-tips-and-/#transitioning-from-pre-school-to-primary-school>