

# In the spotlight...

Everyday heroes who make a difference to people with epilepsy

## Judy Nation, paediatric dietician

Supervising a child on the ketogenic diet is understandably stressful for their parents. But for Judy Nation, it's a deeply satisfying experience. A paediatric dietitian, Judy is one of three staff who run a nationally recognised Ketogenic Diet Clinic at Melbourne's Royal Children's Hospital. Children with hard-to-control epilepsy are admitted to hospital as they begin the high fat, low-carbohydrate eating plan, which in two out of three cases can reduce seizures. Judy carefully calculates exact portion sizes for each child, then monitors and supports them on a menu which includes egg-nog and chicken stir-fries, until they go home around five days later. While Judy cautions that the strict diet can have negative effects both physically and emotionally, she takes great pleasure in helping many children and families on the path to better seizure control.

### Briefly explain your role.

I'm involved with anything to do with food and feeding. This includes assessing suitability for the diet and calculating the diet – this is specifically designed for every child and each meal must have a precise amount of protein, carbohydrate and fat, so that they produce the correct level of ketones. I also educate families about meal preparation and monitoring growth and development. Support is also important as the diet can be very difficult to follow and means that eating for a family is no longer a spontaneous event. Huge amounts of organisation and preparation are necessary and this can be stressful.

### Who sees the best results?

There is some evidence to suggest the diet may work more in certain types of epilepsy syndromes such as Dravet's Syndrome, West Syndrome, and Tuberous Sclerosis. It is vital the family works together to support the child in the changes they must make. Being organised and having a plan for tricky situations like eating out is essential. It is also desirable that a child can tolerate a high-fat



### KETOGENIC DIET – FAST FACTS

- This high-fat, low-carbohydrate diet is undertaken with medical supervision, mostly by children after medication fails to control their epilepsy.
- On the diet, the body burns fat instead of glucose as its primary energy source.
- As the body breaks down fat, it produces molecules called 'ketones.'
- A high level of 'ketones' in the blood helps to reduce seizures in some children, but research is yet to show how or why.

diet. If they can't actually eat the food it will never work!

### Do you often witness personal transformations?

One girl returned to the clinic one month after starting the diet, not only seizure free but behaviourally so much better. She'd stopped hitting her sister and could entertain herself for up to 20 minutes. Her parents said they'd had their first cup of tea together in seven years! We all nearly cried with joy for them.

### You received a travelling scholarship from the hospital...

I visited ketogenic diet centres of excellence including the Johns Hopkins Hospital and the Children's Hospital of Philadelphia in the US and Great Ormond Street Hospital for Children in the UK. I learned how patients were cared for and how the clinics were organised. It was reassuring to discover that as far as patient management goes, we're right up there with the best. What we lack is funding. There are no waiting lists for trialing the diet in the US, at the Royal Children's Hospital in Melbourne a patient could wait up to nine months! Since returning home I'm focusing on ways to decrease these waiting times.

### Can people try the diet at home?

Managing the diet at home, without medical monitoring, is not recommended due to the potential for side-effects including decreased bone density, kidney stones and a child failing to grow. Some children become unwell during their admission for the diet and require specialist medical monitoring and intervention. By monitoring side-effects, through regular blood and urine tests for example, we can reduce the likelihood they'll occur.

### Anything you enjoy most?

Nothing compares to the satisfaction I feel when I'm able to help a family to feed their child tasty, 'normal looking' food that anyone would like to eat. Educating families on meal preparation and supporting a child's growth is what I love to do.

### FOR MORE INFORMATION

Visit the Melbourne Royal Children's Hospital website at [www.rch.org.au](http://www.rch.org.au) or call (03) 9345 7926. Most large paediatric centres also offer a ketogenic diet service. Contact the Neurology Department of a major Paediatric Medical Centre in your capital city.