

In the spotlight...

Everyday heroes who make a difference to people with epilepsy

Kim Jones, support group co-ordinator

By day, Kim Jones is Operations Manager at Lifeline in Newcastle. Her other job is co-ordinating a support group that brings together over 100 people affected by epilepsy for encouragement, information, fun and friendship strengthened by understanding. For the 49-year-old mum it's hard work, but rewarding.

How did you first get involved?

I got a call from another lady who was also interested in forming a support group. There was three of us all wanting the same outcome, somewhere to meet, someone to talk to and the opportunity to learn. An Epilepsy Action [Educator] came along to our first few meeting to establish the guidelines for starting the group.

Describe your role as co-ordinator.

I arrange the monthly meeting. This involves finding and contacting guest speakers, placing community notices in the local papers and on radio. I also do a newsletter every few months and we have a website. I find there is a fair bit of commitment. It's usually evening or weekends. I wish I had more time to commit to the group – perhaps when I retire!

What is the aim of the group?

Sometimes it's hard to talk to friends and family about epilepsy. We provide the environment to talk to others who know what you're going through. The highlight of any meeting for me is the joy you feel when someone has come with questions and mixed feelings, and goes away with answers and the knowledge they are not alone.

Describe a typical meeting.

We have social evenings and formal meetings. We've had many guest speakers. Epilepsy Action Educators have done talks: anything from explaining epilepsy and understanding medication to not forgetting the



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memory workshop! Other speakers have been a paediatric neurologist and dietician. Over 100 people are on our mailing list. Some just like to receive the newsletter, it keeps them in touch. Others come to one meeting or two and then there are the regulars. Each person has a different reason for being there and that's what makes them special.

Who do you know with epilepsy?

Our son Nathan was diagnosed with epilepsy at seven after two tonic clonic seizures. After many visits to neurologists he was finally diagnosed with juvenile myoclonic epilepsy. He's now 21 and is still trying to get that 'just right' mixture of medications. Schooling was hard [but] Epilepsy Action came to the rescue and he was given the extra help needed during his year 10 and year 12 exams. Nathan is music-mad and a talented guitarist – heavy metal of course! He plays in a local Newcastle band called Kindred [and] moved out of home this year – mum was the over-concerned one but all things said, he is doing very well. He has a wonderful girlfriend, Corrine who supports him and

understands. We've had our share of ups and downs, but Nathan always bounces back.

Do you feel supported by the group yourself?

Talking to other people, listening to their experiences and learning from them helps me greatly. The group is always friendly and the formal meetings are an open forum. Several guest speakers have said they know when they come there'll be interesting and curly questions, but that's all part of learning, which is what the group is about – for me and others.

Why go to a support group?

It's a personal choice to become involved but being part of a support group enables you to share experiences, learn more - and most of all you realise you're not alone.

To contact the Epilepsy Support Group of Newcastle call Epilepsy Action on 1300 37 45 37, visit www.geocities.com/epilepsy_au or email epilepsy_au@yahoo.com.au.