



For grandparents

Birth to 2 years

A message from a fellow grandparent

When I first realised that my grandchild had PWS I was very shocked but I soon realised that there were things I could do.

First and most importantly, I wanted to support my family and secondly, I wanted to know as much about the syndrome as I could.

Supporting the Family

I quickly decided that I should allow myself to be guided by my daughter as to how I should treat my grandchild. Particularly where control was concerned. After all, she lives with these problems every day and I was determined not to sabotage her efforts.



Sweets

Most grandparents find it hard to resist the temptation to slip their grandchild the odd pack of sweets but times change and I had already noticed how the parents of our other grandchildren and great nieces and nephews like to limit this type of treat – knowing nowadays just how bad they are for teeth. I decided to leave the giving of sweets to parents and find other small gifts instead.

Weight Control

Some of us have discovered just how much easier it is to put on weight as we grow older, so this should make us more understanding of the ease with which children with PWS gain weight. Weight which, in their case, can be positively dangerous.

Finding Out

It was easy to find out about the syndrome. My daughter belongs to the Prader-Willi Syndrome Association UK, who have published several books and leaflets on the condition and they were only too pleased to let me have some to read.

Equipped with all this information, I felt better able to offer help where I could.

You can also join the PWSA UK as a member in your own right. You will receive PWS Journeys and our quarterly News magazine.



Exercise

Diet isn't the only way people who have the syndrome can keep weight at bay. Faced with the fact that they need fewer calories than the rest of us do, exercise has its part to play too.

We are told that a little gentle exercise does not come amiss in later years. It can be fun to tone our muscles and helps our general well-being. Going for a walk is just as good.

It seems to me that things that we can encourage our grandchildren with PWS to do, can often be mutually beneficial.

Not Easy

I'm not saying that any of this is particularly easy. For us it's remembering these things when our grandchild comes to visit, for grandchildren popping in and out it must be quite difficult. As a family both we and the children have found the Prader-Willi Syndrome Association UK a great source of support. Always ready to answer the odd question if there's something we don't understand or don't know. Why don't you try them?

Other family members

Children with PWS will always need support from their families but don't let us forget that the family needs support too.

How about taking the other children for a few days to give them the chance to enjoy the relaxation of strict eating rules that this can allow? Or taking the child with PWS just for the afternoon, to allow mums to go shopping in peace or for a few days to give the other children a little more of mum and dad's attention?

It may disrupt a routine for a while but it will mean so much to the family.

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