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UNDERSTANDING WILLIAMS SYNDROME BY ADULTS WITH
WILLIAMS SYNDROME -WITH HELP FROM SOPHIE NESBITT,
PROFESSOR PATRICIA HOWLIN AND DR ORLEE UNWIN

INTRODUCTION

This booklet is for and written by adults with Williams Syndrome. It explains what Williams Syndrome is and how it can affect you.

We hope this booklet will help you to understand more about Williams Syndrome.

All the information in this booklet has come from adults with Williams Syndrome.

WHAT IS WILLIAMS SYNDROME?

Williams Syndrome is caused by a missing part of chromosome 7. This affects how the brain works and also causes physical problems. It is something that you are born with. It can affect anyone.

Some people with Williams Syndrome have problems with their heart and kidneys. This means that they might need to see the doctor more often for check ups and perhaps take medicine.

Some people with Williams Syndrome have too much calcium when they are children. This means that they need to eat a special diet. People with Williams Syndrome are often shorter than other people.

Some people with Williams Syndrome have a condition called Hyperacusis. This means that they are scared of loud noises like fireworks and dogs barking. These noises may hurt their ears. They can also get anxious about lots of other things, for example their health or if someone in their family is taken ill. Changes in life like moving to a new home, college or starting a job can also cause a lot of worry and anxiety.

Most people with Williams Syndrome also have learning difficulties. This is why it may be helpful to them to go to special education schools or colleges. They may find it harder to learn things than other people do.

OTHER WAYS IN WHICH WILLIAMS SYNDROME CAN AFFECT YOU

Sometimes people with Williams Syndrome feel lonely because they can find it difficult to get on with other people. This can sometimes make them feel anxious, upset and depressed.

Some people with Williams Syndrome have difficulties with reading and writing, adding up numbers and telling the time. They can make everyday activities like shopping or travelling around very difficult.

Some people with Williams Syndrome find it difficult to remember things that they have been told. It can also be difficult to concentrate on things. On the other hand some people with Williams Syndrome are very good at remembering certain things.

Some people with Williams Syndrome like to collect things like postcards, train tickets, model cars, catalogues or information booklets. This can be fun but can lead to problems if this becomes an "obsession" and if people get too involved in these activities. Also sometimes it can annoy other people who do not understand or share the interest.

THERE ARE MANY GOOD THINGS ABOUT HAVING WILLIAMS SYNDROME

- Being an expert in Williams Syndrome!
- Helping to educate other people, even professionals
- Being able to meet with other adults with Williams Syndrome
- Feeling proud about having Williams Syndrome
- Having a good sense of humour
- Caring about other people and helping them
- Having your family and friends to support you
- Feeling happy and loved
- Meeting all sorts of different people
- Being a member of the Williams Syndrome Foundation

THERE ARE ALSO DIFFICULT THINGS ABOUT HAVING WILLIAMS SYNDROME

- Being scared of loud noises
- People staring and making fun of you
- Not always getting the funny side of jokes
- People asking what is wrong with you
- No matter how hard you try, some things are always difficult
- People can be hurtful. It may be because they don't understand about Williams Syndrome
- Sometimes you feel you let yourself down

LOOKING AHEAD

THINGS THAT ARE IMPORTANT FOR THE FUTURE

- To find out more about Williams Syndrome
- To tell people more about Williams Syndrome
- To learn new things that are useful in everyday life
- To make friends with people who about Williams Syndrome

ADULTS WITH WILLIAMS SYNDROME ARE SIMILAR IN SOME WAYS BUT ALSO DIFFERENT FROM EACH OTHER IN MANY WAYS

- We have different families
- We have different birthdays
- We all have different experiences

"I am different because I have had a kidney transplant"

Nigel Adamson, Nottinghamshire

"I am different because I go to lots of local meetings where I have the chance to speak up for myself"

Tim Holman, West Midlands

"I am different because I was awarded a certificate for a City and Guilds Cookery Course for people with Special Needs"

Caren Crosse, South London

"I am different because I go on business trips with my dad"

Paul Brady, Wales

IF YOU DO HAVE ANY OF THE PROBLEMS OR WORRIES WE HAVE MENTIONED THERE ARE PEOPLE WHO CAN HELP:-

Clinical psychologists

Community Mental Health Teams

Community Learning Disability Teams

Social Workers

Occupational Therapists

Doctors

Community Pyschiatric Nurses

Your carer, daycare manager/ keyworker or your doctor should be able to help you get in touch with one or more of these people.

WILLIAMS SYNDROME FOUNDATION LIMITED

Learn more www.williams-syndrome.org.uk Email us enquires@williams-syndrome.org.uk Call us 01732 365152

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FURTHER INFORMATION

If someone you live or work with wants to find out more about Williams Syndrome there are various resources that might be of interest- Guidelines for Families and Professionals, Guidelines for Employers and Supervisors, Clinical Guidelines, Adult Psychological Guidelines etc. These are available on the Williams Syndrome Foundation website.

The following adults with Williams Syndrome contributed to the development of this booklet:-

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