

Easy reader
Williams syndrome
For adults



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Williams syndrome

People are alike and different.

Everybody has some things that work well and some things that do not. In this information material, things that do not work so well are called **symptoms**.



A group of **symptoms** can be called a **syndrome**, like Williams syndrome.

- It is good to have a name for the symptoms. That helps the medical services know how to treat them.

You can get help and support from your community. You can live a good life. That is what Doctor Peder Rasmussen says, and he knows lots about Williams syndrome.

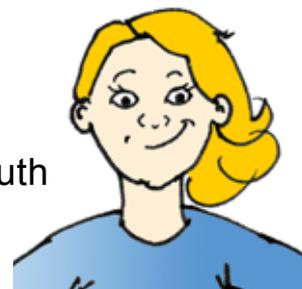
What is Williams syndrome?

People with Williams syndrome may have a number of different symptoms.

short and graceful

a large mouth

talkativeness





Here are symptoms some that are typical of people with Williams:

- *A special appearance:*

For instance, eyes set far apart, a pug nose, a large mouth, little teeth. People with Williams are often short and graceful, with sloping shoulders.

- *Physical symptoms:*

For instance, awkward motor skills, short stature, squinting, hoarse voice.

- *Intellectual disabilities:*

Learning difficulties, for example with reading and writing, concentration, speech and language difficulties.

- *Special behavior:*

For instance quick mood swing, talkativeness, worry and distress, overactivity, and a tendency to be obsessive. Many people are very sensitive to noise.

- *Other things:*

Many people with Williams have trouble understanding how other people think and what they are feeling.

They may find it difficult to play with and cooperate with others. Some people also have unusual interests.

Many people with Williams need clear routines.
They also like to know in advance
what is going to happen.

Lots of people with Williams
are good at seeing details,
but find it difficult to see the whole picture.

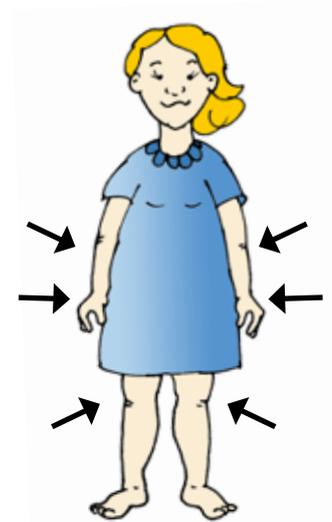
Many are good at recognizing people and
remembering their names.

Lots of people with Williams
find it easy to talk,
but difficult to understand
what other people mean.

- *Symptoms adults may have:*
 - diabetes
 - thyroid problems
 - high blood pressure
 - groin hernias
 - intestinal pockets that can lead to constipation and inflammation

Muscle tension may get too high.
Joint flexibility often decreases.

Adults with Williams may have depressions,
with anxiety and distress.
If this happens,
they will need a great deal of help.



Joint flexibility often
decreases.

How common is Williams?

Williams syndrome is very unusual.
In Sweden, about ten children a year
are born with Williams syndrome.
It is equally common in boys as in girls.

Why does Williams develop?

The human body is made up of millions of
cells.
Different cells have different functions.
Some cells develop into the heart, and
make it work well.
Other cells develop, for instance,
into the kidneys, the skin or the brain.

Each cell is so tiny it can barely be seen.
And yet each cell is fully programmed.
This is called our genetic make-up.

The program determines
what each cell will become and do.
Sometimes the programming goes wrong.
When that happens,
the person may have a sickness
or a syndrome, such as Williams.

Can children inherit Williams?

Usually, a child born with Williams has two
parents who do not have Williams.
This is explained by a problem that
developed in the child's genetic makeup
at conception.

If one of the parents has Williams,
the children can inherit it.

When can you see that a child has Williams?

Children with Williams
have varying symptoms.

If a child has many of the typical symptoms,
it is possible to see
that the child has Williams
as early as infancy.

But some children do not have so many
symptoms.

In those children it might not be clear
that they have Williams syndrome
until they are in school,
or even later.

How is the diagnosis made?

If the doctors suspect
that a child has Williams,
they may take a blood sample.



After the blood sample is analyzed,
they can tell if the child has Williams.

Williams syndrome often includes heart defects

Children with Williams
may be born with a heart defect,
discovered when they are newborn babies.

Sometimes a heart problem can
develop later.

If the child has a heart defect,
the doctors can usually hear a murmur.
Doctor Peder Rasmussen says:
- We can see most heart defects using
ultrasound equipment.

The most common heart defect is called
SVAS.

In SVAS, the arteries that pump the blood
from the heart into the body
are too narrow.
Sometimes other blood vessels
are also too narrow.

They can be widened with an operation.
After heart surgery
it may be necessary to take medication.

High blood pressure

Many people with Williams develop
high blood pressure as they age.
This is because the walls of the
blood vessels get harder.
It is good to have your blood pressure
checked regularly.

Blood calcium

Children with Williams may have
too much calcium in their blood.
If so, it is important
to be careful about the calcium levels
in food and drink.



It is good to have your
blood pressure
checked

Exercise

Exercise is important for the blood circulation as well as for muscles and joints.

A person with a heart defect must talk with the doctor and decide on the right level of exercise.

It is also a good idea to have contact with a physiotherapist.



Exercise is important

Why are people with Williams short?

Children with Williams often come into puberty early.

They stop growing a little earlier than others.

When that happens, they do not end up very tall.

Treatment

A lot of the symptoms need treatment.

It is important, for that reason that adults with Williams have regular health check-ups.

Many people with Williams develop muscle and joint stiffness as they get older.

When that happens, contact with adult habilitation is useful. Adult habilitation is also helpful for people with behavior problems.

Dental care is important

It is important to brush your teeth morning and evening.

If you use fluoridated toothpaste you will have a better chance of not getting cavities.

Support and help in the community

People with Williams often need help and support from the authorities.

There are laws regulating the rights of people with an illness or a syndrome to support and help.

One such law is called LSS, which stands for the law on support and service for some people with disabilities.

You may need help in finding a job or some other occupation.
If you are living on your own, you may also need help to manage shopping and cleaning, for instance.



Dental care is important.

The Health and Medical Act,
is about the right to

- medical care
- habilitation
- personal aids
- transportation to and from
the hospital or health centre

You can get help from the habilitation centre
applying for medical and transportation
services.

Interview

Helen has Williams syndrome

Helen is a 43-year-old woman.
She lives in a nice one-bedroom flat.

Her personal helpers live in the same
building.

Helen gets help with her cleaning, laundry
and cooking.

Helen goes to an occupational centre
on work days.

At the moment
she is packing holiday greeting cards.
She enjoys her work.



Helen enjoys her work.

What was it like growing up with Williams syndrome?

- My parents found out I had a functional disability when I was two years old.

I realized early on that I was different. Maybe when I was about six.

I was diagnosed with Williams syndrome when I was nine.

After that, it took many years for me to understand what it means to have Williams syndrome.

At home we often talked about ways of living with Williams, says Helen.

- I wanted to try going to the same school as my friends. I was not allowed. They said I would not be able to cope with being together with so many people.

Are there things about Williams that have held you back when choosing what to study?

After comprehensive school, Helen went to an adult education centre, a folk high school, for several years.

She recommends that type of school for people with Williams.



She had a room of her own and lots of friends.

She really enjoyed being there.

- We studied, but also had parties and lots of fun activities.



I was really happy at the folk high school. But I did not learn a trade.

Later in life, I applied for jobs that were too difficult for me to manage. Like everyone, I have dreamt of having a good job.

Today I am content with the job I have. Now I accept my disability.

What is the hardest part of being an adult with Williams?

- I would like to have a house, a family and children.

Now I am too old to have children. Most women over 40 have trouble having children.

So now I would like to be with a man who already has children. Maybe we could be a family.

Until then I will make do with my two parakeets. They are my little `children`.





I really like the building I live in.
We are like one big family.
That makes me happy.

I really enjoy spending time
with other people.
My favorite thing is being with my family
and relatives.

Helen says she never feels really free.
She cannot do whatever she wants to.

- I always have to have
one of the helpers with me
when I go out.
I have one personal helper at home,
and one at work.

There is also someone who is my
companion.
I cannot go into town alone.
We usually only go into town about
once a month or so.
I would like to go more often.

Earlier, Helen had a lot of trouble
with mood swings.
Sometimes her hot temper
caused her problems.

- Now I take medication.
I am much better from it.
Much more even-tempered,





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