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NEWSLETTER SUMMER 09

Worster- Drought Syndrome - what is it?

(Also known as "CONGENITAL SUPRABULBAR PARESIS")

This condition is a form of cerebral palsy. The main problems occur with the mouth, tongue and swallowing muscles as a result of the bulbar muscles being affected. There are usually no obvious causes in the pregnancy or birth but some varieties are genetically determined. Because of the range of problems the diagnosis is often made quite late.

It is self evident from observing the children of the group that there is a wide range of abilities between children diagnosed as having Worster-Drought Syndrome.

our aims

- To offer support to other families affected by Worster-Drought Syndrome.
- To raise awareness of Worster-Drought Syndrome with professional workers and other interested individuals.
- To raise awareness of Worster-Drought Syndrome Support Group.
- Support and promotion of any research into Worster-Drought Syndrome

Editor's Note

Welcome to our 'new look' newsletter. It is 'short and sweet' this issue I am afraid as we just want to let all our members know that we are still here!

I am hoping we will soon be back on track with regular issues to keep us all up to date on current issues. I also would

welcome feedback on what you would like to see in future issues so please don't hesitate to send me your ideas and articles.

Nicki Turley

e-mail me on
secretary@wdssg.org.uk



"I joined the WDS Support group in 2004 after searching on the internet, it was the day that changed my life."

"I now knew that I was not alone and there were other people to talk to who have WDS. Before I joined the group I didn't know anyone with this condition or how it effected other people. I wasn't sure how to manage,



it was very isolating. I have made many friends through this group and its given me a new sense of direction. I just wish that when I was younger I could had someone who knew just how it affected me and not feel so alone. I feel its very important to make sure our children have the support from others in this group."

Mark Mayer - Treasurer

"I joined in 2007 after it was suggested my son had WDS and I was desperate to find out more information and to talk to people about it"

Nicki Turley - Secretary

MORE VOLUNTEERS PLEASE

Unfortunately we have had a few problems this year and have not been able to give you all full support and the contact you should expect. We need to remedy this as soon as possible.

Jacqui Leech, our Chairman, has now officially resigned and we are looking for new committee members to come and help us get the support group back up and running again. We will require written nominations for all these committee posts...

Please post your nominations to the Secretary: 84 Frobisher Road, Bilton, Rugby, Warwickshire CV22 7HS.

Chairman
position vacant
Secretary
Nicki Turley
Treasurer
Mark Mayer
Committee Members
also required PLEASE

We are in the process of arranging an urgent AGM to discuss the future of the group and to elect a new, dedicated committee.

PLEASE NOTE - it is imperative that we have a minimum of three executive committee members to keep our charity going.

Due to these unforeseen circumstances there will be no organised family day this year, but you will receive details of where and when the AGM will take place very soon. It will be posted on our website and a letter will be sent out to all our members. A new Chairman will be appointed at this meeting.

We would like to sincerely apologise for any appointment.

Support plans - what are they?

A Support Plans says how you:
want to change your life
will spend your individual budget to get the life you want

MAKING YOUR SUPPORT PLAN

A Support Plan describes what a person wants to change about their life and how they will use their Individual Budget to make these changes happen.

Your local authority has to agree your support plan.

Firstly, you can make your plan yourself by answering these questions:

- What is important to you?
- What do you want to change?
- How will you arrange your support?
- How will you spend your money?
- How will you manage your support?
- How will you stay in control?
- What will you do next?

Secondly, you can use one of the in-control guides from the website www.in-control.org.uk

Thirdly, you could start by filling in a picture template which you can download for free from www.in-control.org.uk

WHAT NEEDS TO BE IN A SUPPORT PLAN?

In order for the care manager to agree the release of money for the Budget, they must be able to see and agree a plan that meets clear criteria.

See their website for a description of the 7 criteria for signing off a support plan.

YOUNG PEOPLE

Support Plan is the name for the plan that shows how someone's Individual Budget will be spent. In order for the care manager to agree the release of money for the Budget, they must be able to see and agree a plan that meets clear criteria.

The website looks at what needs to be in a young persons support plan.

THINKING ABOUT SUPPORT PLANNING

There are four core elements of Support Planning:

- Clear expectations
- A range of ways for people to get support if they need it
- Images of possibility
- A review process

COMPARING CARE PLANS AND SUPPORT PLANS

A Support Plan describes what a person wants to change about their life and how they will use their Individual Budget to make these changes happen. Support Plans should replace Care Plans, rather than trying to run two systems alongside each other.

The website compares care plans and support plans.

CARE MANAGEMENT AND INDIVIDUAL BUDGET PROCESS

Download from the website a description of how the care management process works, and compares this to how the individual budget process works.

PERSON-CENTRED PLANNING AND SUPPORT PLANNING

Person-centred planning and support planning are from the same family and are underpinned by the same values, and both have a foundation of person-centred thinking.

The website shows how person-centred thinking and planning are the foundation of good support planning.

GOOD PRACTICE IN SUPPORT PLANNING AND BROKERAGE

Download their booklet on current good practice, part of the Putting People First personalization toolkit.

SELF DIRECTED SUPPORT

Download their brief one page graphic that defines all of the words that you will hear about self directed support and personalisation.

For more information and downloads go to:
www.supportplanning.org/WhatIsSP



Lets communicate!

Don't forget there are discussion forums on our website which is a very useful way of expressing our views, experiences and sharing our problems with other members. You can access any news updates too.

The forum has been relatively quiet lately so lets get chatting!!

Please log on to www.wdssg.org.uk

Affiliated to Contact a Family and the Rare Disorders Alliance - UK

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