

Letter From The Chairman

Hello and welcome to the first WDS-SG newsletter of 2006. I hope your Christmas and New Year went well.

As a group we are looking forward to this year with several projects that we believe will help progress the group and drive on the name of the condition that affects us all, Worster-Drought Syndrome.

We will be having an AGM this year, which in line with three years ago will be on a smaller scale. The venue will be away from London this time around so it will be easier for our families who live in the northern part of his country. More details to come soon.

One of the biggest projects we are working on is a new and updated information booklet. We have had a booklet for some time but we feel it is time to re-plan and publish it. The most up to date information is being collated as I type and once it has all been sorted we plan to, ultimately, send a copy to every paediatric consultant, speech therapist, neurologist, doctor, social worker, health visitor and indeed anyone who has a professional interest in WDS. This will cost a great deal so we have put together a sub committee to look at all aspects of fund raising.

As I have mentioned committees we have a dilemma this year. The charities commission require that the management committee of any charity stand down after three years of service. As we are in the third year since we became a registered charity we must all stand down at this years AGM.

This is the ideal opportunity for some new blood to come into the team. I have spoken about this before so this time around we have decided to be more pro-active. Each member of the current committee has been given a list of member's names and will be telephoning you all directly, if you have not been called already. The success of the WDS-SG depends on people coming forward to help run the group. I know this sounds obvious, and I am sorry for being blunt, but there is a serious danger of the group becoming stale and not moving forward if we don't have some new people to help run it.

So, if you have something to offer, no matter how little, please get in touch. We have six meetings a year of which three are face to face and the other are by telephone conference. The only thing we ask is that you commit to all the telephone conferences and one face to face meeting.

Moving on to something more positive. I had the pleasure of meeting with a chap called Paul Ashley who is a Paediatric Dental Specialist at The Eastman Centre in London. Paul was keen to meet with me because he wants to gather some data on a condition called small jaw. This is where the lower jaw develops slower than the upper jaw and children with this problem have trouble chewing and swallowing. It is often linked with conditions like Cerebral Palsy and many of our children have this difficulty, along with other aspects like crowded teeth. The upshot is that he would like to get 5 children together at The Eastman to produce a base line study group. The child should be between the ages of 8 and 12 and be available for a half day on a date to be decided. If you would like more information about this please contact me directly on 01376 348948 or by email to

j.gleech@bopenworld.com

Worster Drought Syndrome Support Group

Committee Members



Gavin Leech
Chairman



Monique Lauder
Vice Chair



Mary Rumbold
Treasurer



Hayley Herman
Secretary



Vanessa Butt
National Contact



Jacqui Leech
Committee
Member



Micheal Rumbold
Committee
Member



Graham Spencer
Newsletter
Editor

No Photo
Available

Rene Fullerton
Committee
Member

No Photo
Available

Anita Brown
Committee
Member



Could This Be
You?



Could This Be
You?

We need new members for the committee.

In brief all the committee members need to step down this year as we have been in the posts for 3 years.

We therefore, desperately need new blood on the committee.

We meet 3 times a year and have 3 conference calls.

If you need further information please contact Hayley Herman via email hayleyherman@f2s.com or call on 07866 728661.

We really do need your support – we will be hard pushed to continue without it.

National Contact Report 2004-05

This year I have sent out a steady stream of information packs. I have sent a lot more to professionals working with children with Worster-Drought Syndrome. I know from personal experience with my own son that there are so many who have not heard of WDS.

Professor Neville has just been appointed Prince of Wales Chair of Childhood Epilepsy, as holder of the Chair, Professor Neville will lead Europe's largest multi-disciplinary group devoted to childhood epilepsy. His team will work to develop their understanding of why young children with epilepsy often develop learning and behavioural problems, including autistic spectrum disorder.

Over the years so many of our children have been diagnosed by Professor Neville and the group will miss his expertise but we are very grateful to him as he is still very committed to our children with WDS.

I hope that you will do your part by supporting the condition and group by passing on our information sheets to all the professionals who see your children. This will help us in getting the condition better known.

The table below shows where all our families live as you can see we are spread throughout the UK, Essex and Kent have around the same number; otherwise we are spread very thinly in other counties.

County	Numbers	County	Numbers
Aberdeen	1	Merseyside	1
Avon	1	Middlesex	2
Bedfordshire	1	Norfolk	4
Bristol	1	Northern Ireland	1
Cheshire	1	Northumberland	1
Cornwall	2	South Gloucestershire	1
Cumbria	1	South Yorks	2
Dorset	2	Sheffield	1
East Yorkshire	1	Shetland Isles	1
Essex	11	Somerset	2
Hants	2	Suffolk	2
Herts	4	Tyne and Wear	3
Kent	10	Wales	1
Lancaster	1	Wiltshire	3
Leicestershire	1	Worcestershire	2
Liverpool	1	Yorkshire	2
London	5		
Manchester	2		

It is also clear that we have more boys than girls with the condition and have a few families with two affected children in the family.

One thing that has recently become apparent is that our children's teeth may also be affected by the condition; we are trying to get a group of experts to advise in this area.

We are very fortunate that we have adults in touch with us who have WDS and it is lovely to hear how they are getting on.

Over the years it has become very clear that although all our children are diagnosed with Worster-Drought Syndrome, they can be affected very differently. For some the condition is mild and they can live a normal life while others more severely affected are likely to require long-term support and care.

The group has come a very long way in the last ten years we hope to continue to promote the condition more.

Vanessa Butt

This was written for the groups AGM June 2005

[Carers Week 2006 is 12-18 June](#)

Carers Week this year takes place from 12-18 June 2006, with our theme being In Sickness and in Health. Carers Week is organised by eight leading UK charities - Carers UK, Counsel and Care, Crossroads Caring for Carers, Help the Aged, Macmillan Cancer Relief, MS Society, Rethink and the Princess Royal Trust for Carers. More information about them and the services they offer carers can be found at the carers week website - www.carersweek.org

Carers Week is about

recognising and celebrating the contribution made by carers

campaigning for better support and services for carers

promoting best practice and improving carers' quality of life

reaching out to 'hidden' carers in every community, and ensuring they know where support can be found

For information if you are not on the internet then please contact

CARERS UK

20/25 Glasshouse Yard,

London

EC1A 4JT

Telephone 020 7490 8818

Fax: 020 7490 8824

E-mail: info@ukcarers.org

Website: www.carersonline.org.uk

WDSSG Internet Forum

The committee has decided to set up an Internet forum for the members to discuss issues about WDS. Although the primary object is for discussions on WDS, the forum can be used by the members to air issues on any subject.

There are two main sections of the forum, one that is open to the public and one that is for members of the WDSSG only. The Public area is viewable to anyone, although you will need a to create an account to post replies there. We decided to do it this way because there are people who can't join the group for various reasons but would still like to exchange information and talk to the families. The WDSSG members only section only viewable by group members and we suggest you use that area if you want to post any personal information you want to keep within the confines of the group.

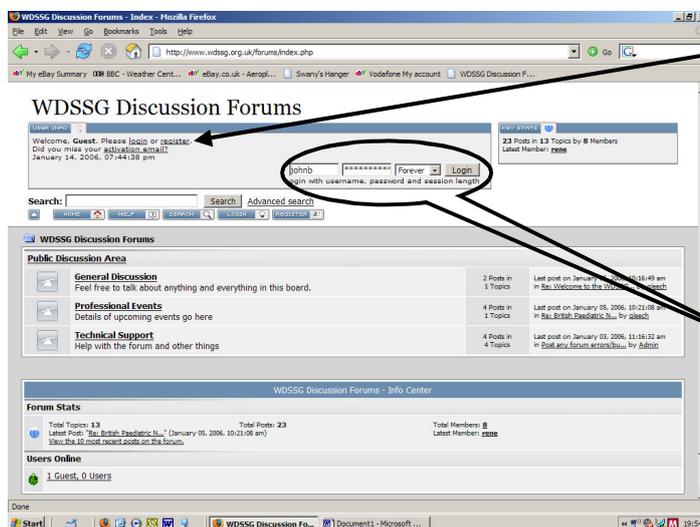
So the main questions are how do I use the forum and how does it work?

Well the forum is based around the idea of discussions, or "threads". A thread is like a conversation, with replies being linked onto the bottom of it in chronological order. The advantage over a normal conversation is you can go back and read what people have said before you! On large forums, some threads can have hundreds or even thousands of replies chained onto the end of them. So if you want to start a new topic of conversation, start a new thread, and if you want to join in on an already started conversation, click the thread and click reply.

Now go ahead and give it a try by following these simple instructions.

Connect to the forum login page by going to <http://www.wdssg.org.uk/forums> by clicking on this link or typing it into the address field of you web browser.

The forums are only available to people who have first registered, so this is your first step, once registered you never need do it again. Click on the register link in the top left hand box.

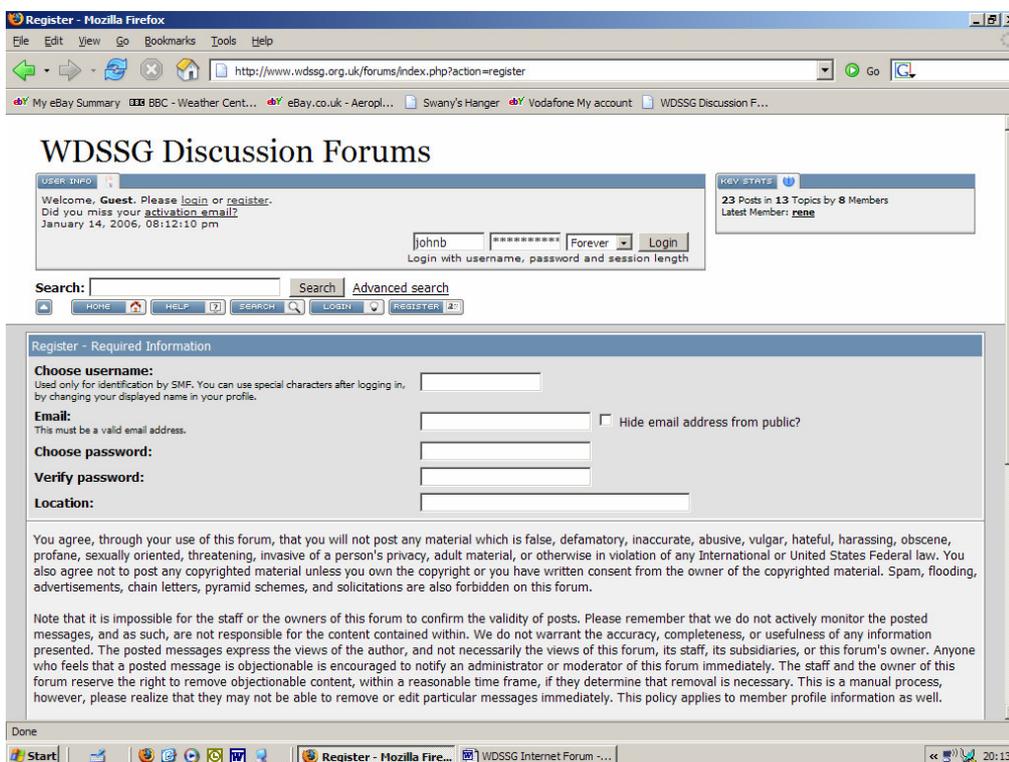


To Register
Click here

Logon here
Once you have
Registration is
accepted

This will take you to the registration page where you are required to give a user name (this is the name you will be known by on the forums), email address to be contacted on, the password you wish to use to access the forum and your approximate location (Just a town name or even country will do).

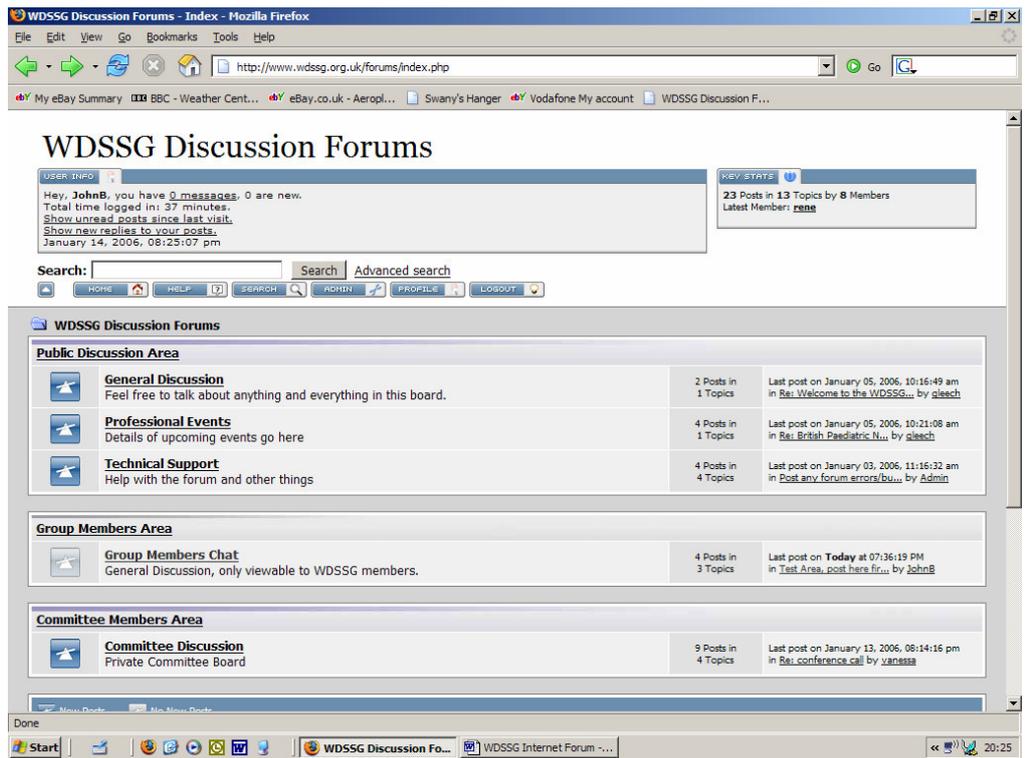
Read the terms and conditions and if you agree tick the box and click on the register button at the bottom of the page.



Now you have to wait until you receive an email confirming your registration to the forum. There is a link in this email, which you have to click to finish the registration process.

Once your registration has been accepted you can log on by entering the username and password you gave when registering. See screenshot above.

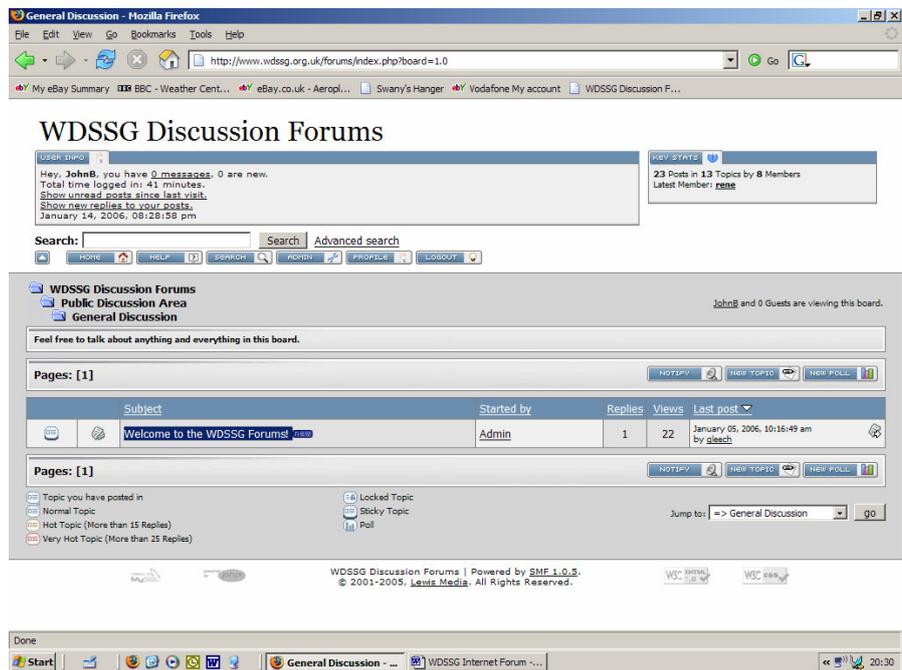
Which will take you to the following page.



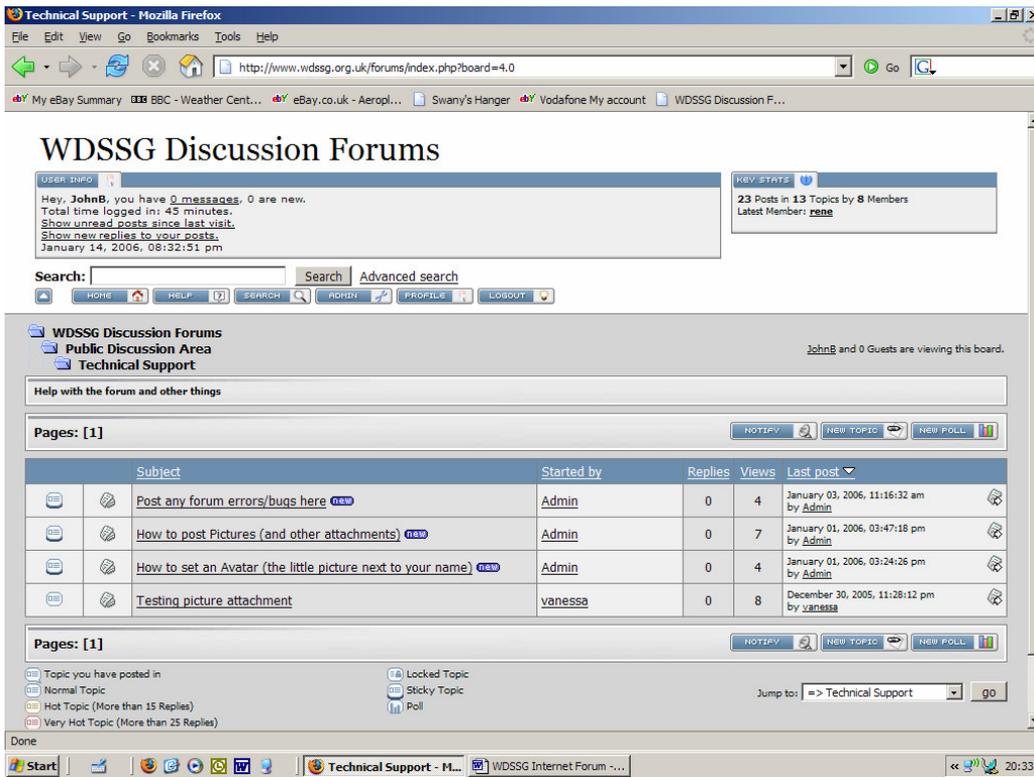
Now you are logged in and ready to go, try it out, you can't do anything wrong! Don't worry about breaking anything, this is a learning process for all of us really, and if you don't try it out, you won't learn!

The following are a few areas to try first.

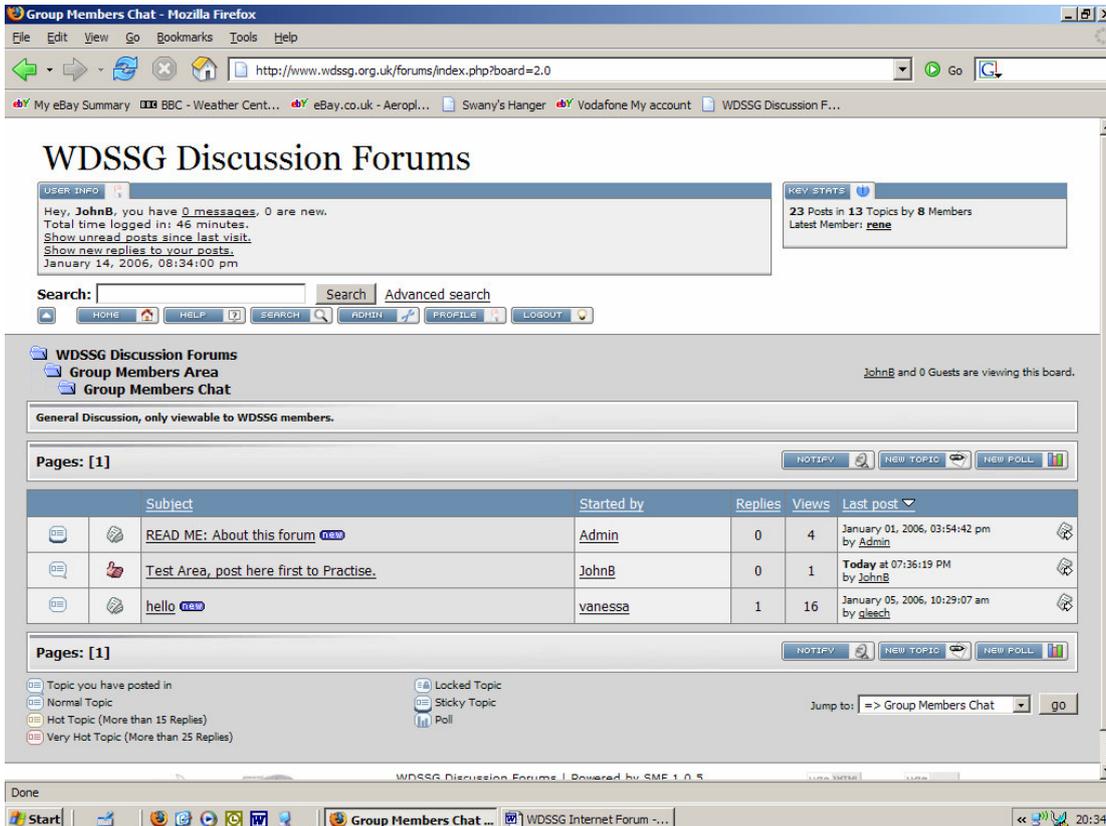
General discussion area, then the Welcome link.



Any problems, try the technical support area.



Or go to the member area and try a test posting in the test area, start off by just saying Hi.



Hope this is enough to get you going, just experiment upload a picture, update your profile, start a new thread... go on and have a go!

A few general etiquette guides:

- If you are offended by something that has been written, please take time to read through it again and check you haven't misinterpreted it. It is easy to get your wires crossed and jump off at the deep end when the other person may have been joking or simply just made a typo.
- Similarly, please make sure you make it clear what you are trying to say - this is what the little "smilie" icons are for! Also try to use correct punctuation and spelling where possible, it just makes it easier for everyone to read.
- Please read threads before you post a new reply to them.

Most importantly: Have Fun! You get to talk to people from different walks of life from all around the world. How great is that?!

If you get stuck try the help pages or start a new thread on the technical support section and the administrator will respond to you. If that doesn't work, email admin@wdssg.org.uk for direct help.

Remember, if you post in the Public Discussion Area, its available for all to read. If you want to have private discussion between members - post in the Group Members Area.

Also: remember to log off when you have finished if you are using a public or shared computer.

Good luck

[Family Day 2006](#)

This years family day is to be on the 2nd July at Wolvey Village Hall (near Nuneaton).

Details to follow shortly through the post.

One More Step

We knew from an early age that we wanted Martin to be as independent as possible, John and I are not getting any younger and with WDS being a non progressive disorder we wanted to plan for his future rather wait for an emergency situation where he may not get any choice of the services available to him.

So we have been working on this aim since he was thirteen/fourteen, when we had his transition review we discussed how this could be best met. It was decided that the local college provision would not be right for him, this was the decision of the professionals that knew him, and so we had to decide what else was available. The idea of him leaving school at 19 without any help was not an option.

We decided to look around the country for specialist residential college placements, with help from our Connexions Advisor we short-listed six such colleges, we made appointments and set off around the country. Out of the six we decided that two would be suitable, both had pros and cons but in the end after two, three day assessments at Portland College Martin decided that he wanted to attend Portland, in fact he told everyone there that he would see them in September even before they had accepted him on the course! As you can imagine this process of visits and assessments takes a long time so it is important that you start the process early. We found that it very important to see the individual colleges, as they all are very different and had different strengths.

Martin is now 22 and is in his final year at Portland College. He is on an Independent and Daily Living Skills course at the College, he has really flourished and better still, he loves it there. He has made lots of friends including Mark who many of you know from the family day, Yes we did have a few hiccups the first term but that is not surprising after being in a very sheltered environment at school but this year he is learning to live in a flat sharing with two others.

Over the last few months we have been working on Martins Persons Centred Plan this has been such a worthwhile project as Martin has taken an active role in deciding what he would like to do when he returns to the Ipswich Area.

We are now looking at the next step when he finishes in July but that is another story and you will have to wait for another instalment.

In retrospect, it takes longer than we thought, **“NO MUCH LONGER”** than we thought to do all this. So our advice would be to say to any parent who would like to send there child to a specialist college, you need to think two to three years ahead. I.e. Start looking for a college when your child is 16... and start a PCP now they really work with the local authorities.

See the links below for were to get help.

John and Vanessa Butt

If you would like to look for more information on transition then this list may help you

[Contact a Family](#)

Produce a fact sheet Transition in England and Wales and post 16 Transition in Scotland It explains the Transition Plan.

Helpline on 0808 808 3555. Freephone for parents and families (10am-4pm, Mon-Fri).

You can always look on their web site

<http://www.cafamily.org.uk/transition.html>

[Connexions](#)

Connexions Direct can offer you all the information and advice you need to make the decisions and choices in life.

If you do not know where they are located in your local area then

Call Connexions Direct on 080 800 13 2 19 If you are on interent then there web site will help you find your local branch

<http://www.connexions-direct.com/index.cfm?pid=74&catalogueContentID=375>

[The Association Of National Specialist Colleges](#)

To request a Natspec Directory then contact

Kevin O'Brien
Chief Executive
39 Sanders Rd
Quorn
Loughborough
Leicestershire
LE12 8JN

kevin.obrien43@ntlworld.com

If you have internet access then all the information can be found at

<http://www.natspec.org.uk/>

Person Centred Plan

We published some information on PCP in our last issue of WORDS but if you would now like to know more then look at

http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm

Or contact

Circles Network,
Potford's Dam Farm
Coventry Road
Cawston
Rugby
Warwickshire
CV23 9JP

Tel: 01788 816 671

Fax: 01788 816 672

Here are some other Internet sites that you may find helpful

<http://www.everychildmatters.gov.uk/socialcare/disabledchildren/transition/>

<http://www.myfuturechoices.org.uk/>

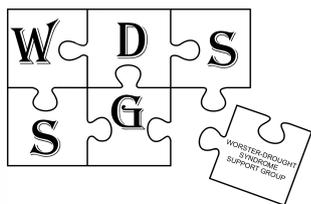
<http://www.myfuturechoices.org.uk/>

Benefits

Are you getting all that you and your family are entitled to, if you are unsure what is available then please ask you health visitor, social worker, CAB or you can look directly on this link below.

<http://www.direct.gov.uk/DisabledPeople/fs/en>

From the age of 16 be aware that you can claim Incapacity Benefit instead of Child Benefit for your disabled young person.



We are always looking for articles for the newsletters so please email them to the editor at words@wdssg.org.uk

We would gratefully receive short stories, personal insights, poems, funny stories or indeed anything that you might consider useful. Generally we keep the articles as sent but sometimes it may be necessary to edit them slightly for various reasons.

The Editor and The Worster Drought Syndrome Support Group do not accept any responsibility for the views of contributors expressed in this newsletter.

The cut off date for the next newsletter will be Mid April.

From the next issue, we hope to send the newsletter by email so it is very important that you send us your correct email address on the registration form.

Don't worry if you are not on email we will send you the newsletter through the post as normal.

[Carers urged “Don’t miss out”](#)

A new guide is available that tells carers about their pension entitlements - and encourages them to take the necessary steps to boost their income before April 2006.

The leaflet “State Pensions for carers and parents – Your guide” will be available in doctor’s surgeries, Jobcentre Plus offices and local Pension Centres.

It can also be downloaded from www.thepensionservice.gov.uk