WORDS

ISSUE 15

October 2004

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Family Day At London Zoo 2004

Tom And Sister Enjoying Lunch.

What an amazing day had by all. The venue was again, brilliant. The Special Needs Day at London Zoo was well organized and our children all had an incredible morning in the Zoo. Even the weather held up for them in the morning (although the afternoon wasn't too great!). Whilst the kids where taken around the Zoo by The Log Cabin, our talented escorts! The parents were able to hear the quickest AGM on the planet! We heard a wonderful presentation from Andrew Lysley and Rachel Moore from Ace. Our panel of experts for the Question and Answers Panel showed up and didn't disappoint. Our speakers included Professor Neville, Katie Price MA DipCST and Nicola Jolleff from the Wolfson Centre, All of whom, I'm sure you will agree, were informative. We really appreciated the fact that they gave up their time to help us. The format for next year's Q&A will be changing, in response to your feedback, but we will let you know nearer the time on our plans.

On behalf of the committee I would like to thank The Children's No1 Foundation who sponsored our event and all our members for making our special family day so memorable.

Professional Day

One of the aims of the group is to get more Professionals aware of the condition we are sure you are still met with silence when you say your child has Worster-Drought Syndrome.

So it is very exciting to announce Professor Neville is organising the first ever Professional Day on Worster-Drought Syndrome, with speakers from around the world, the group will be doing a presentation on the day so they the professionals learn more about our families.

More information will be published later but the date for your Diaries is Friday 24th June at the Institute of Child Health London as this is a professional day there may be some cost for attending. Parents will be most welcome to attend this day. We will update you in future newsletters with more details.

If you are unable to attend the Professional Day on the Friday we are holding our AGM/ Conference/Family Day on Saturday 25th June 2005 in London when there will be feedback from the previous day. Monique and her merry band are at present organising the day and more details will follow.

National Contact Report 2003-2004

Over the past year the group has had many requests for information on Worster-Drought Syndrome from home and abroad.

These have included requests from doctors, speech and language therapists, schools, classroom assistants, and Parent Partnership schemes.

We have 125 families on our mailing list, of which, 8 families have Congenital Bilateral Perisylvian syndrome or related conditions.

We also send out our newsletter to those who have an interest in the syndrome abroad as they feel very isolated because they have no support.

We have had an increase of 22 families from last year, which is a big rise for the group. This has been helped by the groundwork that the group has done over the last few years to get the syndrome better known.

In the past year we have put all the family details on computer and I have undertaken a computer course, which should enable me to do this better. I must thank the 35 who filled out the child data forms.

I have produced a list to show you where all the children come from, as you will see Essex has 17 families otherwise we are spread very thinly in other counties. So you can see that your child may be the only child in the county with WDS so please help us by photocopying all the information and passing it on to any professional working with your child.

This will promote the syndrome and the group.

County	Numbers	County	Numbers
Essex	17	Cumbria	1
Kent	14	Ireland	1
London	8	Hants	1
Surrey	4	Bristol	1
Middlesex	4	Dorset	1
W Sussex	4	Scotland	1
Northern Ireland	4	Hull	1
Wiltshire	4	Cardiff	1
Herts.	3	Shetland Isles	1
Norfolk	3	Hampshire	1
Tyne and Wear	3	Yorkshire	1
Lancashire	3	South Yorkshire	1
Suffolk	2	Derbyshire	1
Merseyside	2	Southampton	1
Sheffield	2	Northumberland	1
Dorset	2	Staffordshire	1
Birmingham	2	Oxfordshire	1
Bedfordshire	2	Liverpool	1
Worcestershire	2	Malta	1
Cheshire	2	Cornwall	1
Somerset	2	Shropshire	1
Doncaster	1	Wirral	1

If any family would like to be linked to others then please get in touch with me. vanessa@buttsco.co.uk or telephone 01473 240761 but as you can see you may have to travel some distance to meet especially if you are the ones who live in Cornwall, Northumberland or Cardiff etc.

Answers to questions in the Questions and Answer Session during the meeting held at London Zoo on Saturday, 12 June 2004

Is WDS genetic?

WDS is not one condition, but a group conditions that share common clinical characteristics. It is likely that there are several causes, including in some cases genetic defects in the development of the perisylvian region (area of brain that controls movement of the mouth and throat) and others sporadic injury to the developing perisylvian region, particularly toward the end of the first trimester of pregnancy. It is not always possible for a given child, to identify the cause.

WDS is a clinical diagnosis, and there is no 'test' that detects it. In some children, a brain scan will show an abnormality in both perisylvian areas (also known as congenital bilateral perisylvian syndrome). In other children, the abnormality may only be seen on one side. For the majority, no abnormality can be seen with the current imaging techniques. When present, the perisylvian abnormality is consistent with polymicrogyria, which is an abnormality in brain development that occurs early in pregnancy, around 16-20 weeks after conception. The presence of the perisylvian abnormality does not signify a particular cause, and may be found in genetic and non-genetic cases.

Family groups, where more than one person is affected by WDS are well recognised, and represent a significant minority of people affected. They can occur with or without imaging changes, and for some families, affected members have different imaging findings. Several different patterns have been seen within the family groups, suggesting that there is more than one gene or pattern of genetic inheritance at work.

When families have one child with WDS, they would be given an approximate recurrence risk of 1 in 10 that WDS might affect subsequent children. This is similar to the level of recurrence risk given in other cases of unexplained cerebral palsy. However, these families will be a mixture of some families who in fact have a high risk and others who have a low risk (as at present we cannot identify those cases that are genetic until there is a second affected person). In general the risks for siblings of a child with Worster-Drought syndrome, of having children of their own affected by the syndrome, is lower than the above risk and for many it will be no increased risk. However, the current evidence suggests more than one pattern of inheritance, including an 'x' linked pattern in which the sister of a boy with Worster-Drought syndrome would need specific genetic counselling as it may be inherited through the female line.

It is our hope that the genetics will become much clearer over the next 5-10 years so that much more precise genetic counselling can be offered. We hope to work with the WDS Support Group, and a Genetics Research Group in USA, to begin to address these questions.

WDS is undoubtedly under diagnosed. No prevalence studies have been done. Cerebral palsy is known to occur in around 3 in 1000 in the general population, and WDS is probably around 10% of this rate.

How does WDS affect Speech?

- At what age is a child fully developed in speech and language
- Why do older children not receive as much speech therapy as younger children?
- Does conventional Speech Therapy work with a child who has WDS or do they need something extra?
- If the child does not develop speech, what alternatives do the panel recommend we use?
- What guidelines, if any can the panel recommend on creating the most effective layouts for AAC?

How do children without speech learn to read?

Communication skills

Children's skills in communication develop through out their life. The contrast will be made here between speech and language and communication for many children with Worster-Drought Syndrome, speech is one of the most difficult skills for them to achieve. This is because the muscles of the mouth/palate are often the most severely affected, and because speech is a very rapid, very precise motor skill where even the slightest difficulty in co-ordinating movements can produce significant changes in speech intelligibility. So for all children with cerebral palsy, speech in itself probably reaches best intelligibility levels towards the end of the primary school years (age 10): again, we are very short of studies in this area, but this statement is made on pooled clinical evidence from specialists in the field.

Language (understanding sentences, producing more complex phase, learning new vocabulary) continues through life, although into secondary years this process can be seen to slow down, and such progress may be very slow.

Communication (ability to interact/participate/enjoy conversation/contribute in class) can be promoted throughout life, and many children will benefit from additional, non-speech, methods of communication (signing, gesture, use of printed symbols, voice output communication aids). There IS some evidence that these methods can improve functional communication , and our team are keen to contribute to the discussion about the role of these methods for children with WDS.

2. Prioritisation of resources is part of the caseload management, and the patterns of development as described above, determines that younger children have more access to speech and language therapy monitored and evaluation. We would argue that children in secondary school should have at least annual review of speech intelligibility (measured with an instrument such as the Children's Speech Intelligibility Measure), and review of the relevance of alternative/augmentative methods of communication to support their speech.

See(1) above for "does speech therapy work?"! A recent review of ALL (11 in total) the scientifically sound papers they could find on this subject (for all children with cerebral palsy) had to conclude the following:

Firm evidence of the positive effects of SLT for children with cerebral palsy has not been demonstrated by this review. However, positive trends in communication change were shown. No change in practice is recommended from this review. Further research is needed to describe this client group, and its possible clinical subgroups, and the methods of treatment currently used in SLT. Research is also needed to investigate the effectiveness of new and established interventions and their acceptability to families. Rigour in research practice needs to be extended to enable firm associations between therapy and communication change to be made. The "something extra" may be a concentration on the child's total communication, and would include, as we have said, a discussion about the relevance of other non-speech methods (signing/symbol use etc.).

Eating and Drinking

- Is gastrostomy feeding common in children with WDS
- Is there any proven method that can help a child learn to chew?
- What food supplements, if any, do you recommend for a child with WDS?

Eating and drinking

1. The range of difficulties around mealtimes for children with Worster-Drought Syndrome does vary enormously. Some children will have relatively few problems with chewing and swallowing. Some more significant difficulties, and some will have such poor co-ordination/strength of muscles that it will actually be safe for them to continue to take food orally. It is this group of children for whom gastrostomy feeding may be considered an option.

There are different reasons for a gastrostomy to be considered. In addition to safety reasons (to reduce the risk of children inhaling food/drink particles into the lungs), gastrostomy may be considered where children are failing to gain enough weight to keep healthy and for their brain and body to develop. It is becoming increasingly recognised, both clinically and through studies that children's development can benefit greatly if additional methods of feeding are used where there is inadequate oral intake for good nutrition.

2. As in other areas of therapy intervention, there is a lack of research study evidence around the intervention for feeding and their results. There is no proven method of improving a child's chewing patterns. A speech and language therapist can advise on many aspects of feeding, including the promotion of tongue movements, but any progress will depend much more on the neurological basis of the motor pattern, and the extent of the neurological damage identified. Most children make some spontaneous progress, even slowly, with their muscle patters as they grow, simply with neurological maturation. It is not clear if speech and language therapy can accelerate their process, and claims that intensive/expensive methods cam accelerate "natural" progress should be examined carefully.

3. Supplemental feeding recommendations need input from a dietician. Full supplemental feeding (through gastrostomy tube feeding, or naso-gastric tube) have all the nutritional requirements that will be needed, including vitamins and minerals. Sometimes dieticians will recommend calorie-adding supplements for a child who is eating orally, but requires "top-up" intake (e.g. Duocal/Calogen).

How is the behaviour of a child with WDS affected by the condition?

From studies to date, we know that around 40% of children with WDS have significant behavioural difficulties, particularly in areas such as hyperactivity, poor attention span and social communication. There is no specific behavioural pattern associated with Worster Drought. Many of the behaviours are seen in other children with learning difficulties, in particular, those with epilepsy and social communication disorders. It is important to undertake a clear analysis of any difficulties, as they may require specific treatment, behavioural or educational approaches. A Clinical Psychologist can undertake an analysis and it will be important to determine what has triggered a tantrum for 'no apparent reason'. This may be due to a sudden loud noise, proximity or change of expected routine, as well as the more obvious reasons like not having their needs met quickly enough. It will be important to identify what rewards the child is gaining from the behaviour and think about how this may be changed. There are many techniques which may be useful, particularly those used with children who have an autistic spectrum disorder.

Useful references are:

1-2-3 Magic: Effective Discipline for Children 2-12 by Thomas Phelen

ISBN 0-9633861-9-0

Callenging Behaviour and Autism – Making Sense, Making Progress

Published by the National Autistic Society

It is also increasingly recognised that having a neurological impairment brings out the genetic behavioural pattern

Eating and Drinking

The majority of children with WDS (>90%) have difficulties with feeding at some stage. Feeding difficulties are most common in infants and younger children, and there is a distinct improvement in feeding abilities for most children with time, although many will always need a modified diet (e.g. avoiding particular textures such as apple skins or crisps). Around a quarter of children will need tube feeds at some stage, most commonly as infants. However about 10% will require long term tube feeding, and this is often provided for by a gastrostomy.

An important aspect of feeding difficulties is to know that although they may show steady improvement they may be very difficult to manage without a gastrostomy for the first one to two years of life and that it is not just a matter of physical survival during that time but of keeping relationships going, including during feeding, and not creating massive negativity related to it.

Is it necessary for a child with WDS to have an MRI scan?

WDS is a clinical diagnosis, and the scan result (presence or absence of perisylvian polymicrogyria) will not change the child's management. However it may provide a more complete understanding of the individual child and help to exclude alternative diagnoses. It does not however separate genetic from non-genetic varieties of WDS though the presence of the typical abnormality does seem to increase the chances of epilepsy. It may also be informative for future studies of causation. This must be weighed up against the fact that many children will need sedation or even a general anesthetic to have a scan.

Some children with WDS drool constantly. Why is this?

The majority of children with WDS have some problem with drooling, although this may improve with age. Drooling is caused by the lips being open, lack of regular swallowing and sometimes by the mouth being tilted forwards.

Simple positioning techniques, with a head-up posture, keeping the activities in front of a child as high as possible so that gravity assists their swallowing is important.

Attempts to train people to swallow more frequently (e.g. attempted habituation to noises every 20 seconds) require an extraordinary degree of compliance, and have not been very successful.

Drugs can be used to dry up the secretions, but carry a risk of dental caries and gum disease, as well as side effects such as a constipation, irritability and sometimes blurred vision. Glycopyrrolate is the most commonly used drug for this, and is successful in significantly reducing drooling in most people. However, at least a third of people discontinue it because of the side-effects. Hyoscine patches have also been used.

Botox has been used, particularly in adults with other neurological diseases, to control drooling. It dries up secretions, and therefore also has the risk of increased dental and gum disease. It involves injections which need to be repeated every 3-4 months, which is not usually acceptable for a chronic condition such as Worster-Drought syndrome.

Some surgical techniques involve removal of salivary gland tissue or tying off of the salivary ducts to dry the mouth, and will need extra care of teeth and gums because of the dry mouth. Where dribbling persists beyond the age of 5-6years, transplantation of the salivary ducts can be very helpful (i.e. redirection of the salivary ducts backwards to divert the saliva towards the back of the throat so that it is swallowed rather than dribbled). Children will need careful assessment before such surgery, since for some children who are unable to swallow safely or who cannot deal with the increased saliva volume, this procedure can be dangerous as they cannot protect their airway and may be at risk of aspiration (e.g. swallowing the saliva onto their lungs). Surgery should always be combined with speech and language therapy input to maximise its efficacy. Some research papers on this subject are enclosed.

GOSH is, rightfully, considered to be the centre of excellence for WDS, however not everyone has access to the expertise offered there. Are there any other centres nationwide that can offer the same service as GOSH?

Appropriate services for children with Worster-Drought syndrome should be available nationwide. All regional level centres should be able to provide comprehensive assessment and management for children with complex neurological diagnoses, communication impairments, dysphagia, epilepsy and behavioural impairments. These centres should have a network that links with the local child development services and schools to provide for the needs of most children.

Both specialist and general child development/neurodisability services have been relatively slow to develop in the UK. Resources might be best invested in a family care worker who knows the facilities that should be available in the UK, can assist families in accessing appropriate local services and can monitor progress and facilitate implementation. This, of course, assumes that the child has been identified as having Worster-Drought syndrome. In many areas of the country, children go undiagnosed and are therefore unable to access the comprehensive services they require. We hope to address this with targeted professional training and heightened awareness, and will liaise with the WDS Support Group over this.

Brian Neville, Maria Clark, Nicola Jolleff

14 June 2004

News from the Group.

For those who do not know about the history of the group, Jane Thorpe a parent of a child with Worster-Drought Syndrome formed the support group ten years ago.

When her son was diagnosed, there was no information available other than the report written by Dr Worster-Drought. For those that have seen this will know you need a medical degree to understand all the medical jargon

Through her contact with Contact a Family the group was born and we have come a long way in that time, information packs for parents web site, linking of families, newsletter, charity status organising family days and more.

We have now reached a crossroads and to further the work of the group we need your help and support. Since the group was formed we have relied on the generosity of the committee and donations from our families to run the group but it is time to get the group self financing and the only way we can do this is to ask parents for a £10 voluntary donation. We hope that you can support us in this way.

The other way you can help us to by filling in the groups registration forms, which you will find, enclosed with this newsletter. To comply with Data Protection Act we need up to date information, so this year we are sending out new forms for everyone to fill out. It is so important that you do this and reply to us by 10th November 2004.

Professor Neville is hoping in the near future to do a genetic study so we need you to send the forms back so we can pass on the contact details of the families to the team doing the research.

If we do not hear from you then we will remove you from our mailing list.

Lastly the committee wish to thank everyone for their support, the group can make a real difference to the life of our families, we hope that you will help us to make this happen.

Vanessa Butt

Vice Chair

Fledglings

Fledglings is a not-for-profit organisation which helps parents and carers of a child with special needs of any kind to find simple, affordable solutions to practical problems.

They offer a free product search service to locate toys, clothing, developmental aids and other items which may stimulate the child's development or give relief to the carer. Many such products are kept in stock and They can obtain many more from the wide range of manufacturers and suppliers we deal with.

Once They have located a suitable product, They are usually able to supply it and to do so at a competitive price.

Who can Fledglings help?

Anyone who cares for children with special needs of any kind: parents, grandparents, childminders, foster carers, playgroup leaders, nursery nurses, after-school club leaders, health visitors, etc.

How can Fledglings help you?

Fledglings can help by searching for, ordering and demonstrating products to help with your child's specific development and learning needs. They specialise in finding those unusual items which may not be easily available or those designed specially for children with special needs.

For more info see their web site at http://www.fledglings.org.uk/

GAVIN LEECH

Gavin our chairman has been unwell over the last few months. I am sure that you join with us to wish Gavin a speedy recovery and we send our good wishes to him and Jacqui.

The committee has elected Vanessa Butt as Vice Chair to represent the group until such time Gavin is back on board.

The INPP Exercise Programme

The Institute for Neuro-Physiological Psychology (INPP) aims to research into the effect of central nervous system dysfunction's on children with learning difficulties and adults suffering from neuroses, and to develop appropriate remedial and rehabilitation programmes, concentrating on the role of the cerebellum in movement, balance and co-ordination.

Each of us is born with a set of primitive reflexes which should be controlled by a higher part of the brain during the first year of life. If these are not fully controlled in infancy, the brain cannot gain adequate control over vocabulary, skilled and complex movements causing neurological developmental delay (NDD).

Symptoms may include problems with control of eye movements – tracking (necessary for reading), changing from near to distant focus and back again (necessary for copying from white / blackboards),

hand / eye co-ordination (necessary for writing), physical co-ordination and balance, processing, memorisation and retrieval of information.

Remediation is to replicate movements which should have been made at the appropriate stage of development, through daily exercises, to 're-programme' the brain. Everything is backed up by sound medical research and evidence.

Anita Brown a parent member of the WDSSG took her son Thomas along for an exercise programme that would help with his balance and general co-ordination and a listening programme – a sound therapy course - to stimulate his listening skills and help with articulation.

After 18 months, both Anita and Thomas's therapist were delighted with his progress. Anita said Thomas really enjoyed the programme and Liked doing the exercises. He would remind her that he had to do the exercises each day. His co-ordination improved e.g. kicking a ball and running

They would go to the INPP every 6-8 weeks for a review and new exercises to do. It was one of the programmes they have done where they have actually seen a result. Anita was really glad that they tried this one and so is Tom as now when he kicks a ball it goes a long way on his first kick instead of many.

For any further information about the work of the institute the INPP web site is www.inpp.org.uk

Elliot's Communication

While we all realise how vital it is to enable our children to communicate effectively, implementation of strategies can be an absolute nightmare - at least this has been our experience with Elliot - and so I thought it might be a good idea to write an occasional piece for the newsletter discussing this, and our hopes for the future.

Despite his speech difficulties Elliot is often a good and effective communicator, especially with those who are familiar listeners. He always vocalises when communicating and all of his vowel sounds plus a few of his consonant sounds are consistently clear. In addition, his syllable and word lengths/shapes and sentence constructions are largely normal too. However, where Elliot is unable to produce particular sounds, he tends to 'substitute' with something that he can use e.g. 's' becomes a sort of 'f' produced with air escaping from the nose and a facial grimace/screwed up nose.

Elliot supplements his speech with signing - particularly Makaton, - a lot of gesture, and a communication aid that is on a lap top computer. In addition to this we are currently trying to introduce a palm top computer, for more 'social' communication.

At a very young age Elliot began inventing his own signs, some of which we still use now! When he was about 3 ½ years old we were introduced to some basic Makaton signs and we all continued learning these at Elliot's first school where there were regular evening classes for parents and carers. We learnt a great deal but, if we are honest, we've found it difficult to always use signs ourselves because a) Elliot knows what we are saying without them, b) using signs actually slows speech down, and c) often, when in conversation with Elliot, we are using our hands for other things such as peeling the potatoes or washing up! Of course this means that we sometimes feel very guilty when we realise that we haven't consciously signed all day, as we are well aware that a signing environment is necessary in order to encourage and extend his abilities.

At Elliot's second school a different signing system was used called Paget Gorman. This is a more complex and grammatical signing system and it requires greater dexterity of the hands - a big problem for Elliot because of his poor fine motor skills - he still can't do up or undo buttons, put zips together etc. So although this school was very good for him on many levels, signing was a problem for him.

Back at his first school, Elliot was also provided with a communication book, which used Rebus symbols, pictures, photos and text. This evolved over time and helped him with classes, topics, social chat and home/school communication, however aged about 8 years he just decided that he didn't want to use it anymore and so wouldn't take it to school, it was as though he felt he had outgrown it suddenly. During this time Elliot also had a small communication aid (a Messagemate) on which 32 short messages could be taped. He did use this at school in some structured situations, but he failed to see how it could be helpful elsewhere. The truth is he often used to take it out of his bag to 'play' with, but that was as far as it went. On reflection I think that this aid was a bit of a novelty to start with, but was too limited for him.

About two years ago, aged 9, it was decided that as - due to his poor motor skills - Elliot required a computer for schoolwork, it would be a good idea to have a communication aid actually on his laptop. This took some time to put in place, as these things always seem to, but he now has a system (The Grid from Sensory Software) on which pages/grids are created using PCS symbols, photos and pictures downloaded from the net, together with text. This means that in addition to planned pages for specific topics in lessons, other pages have been created that he really wants to use e.g. he is heavily into football and likes to discuss matches, scores and players etc., so we have created pages that include photos of his favourite players, the team logos, scores and a series of comments that he can make about matches, as well as questions that he can ask. We have also downloaded photos of animals and birds and been able to create whole pages of comments and information about his favourites such as buzzards and red kites. However, it has taken a great deal of time to learn how to use the software and get around its quirks, come up with the best layouts etc, so it is only in the last 6 months that this has offered him any real potential for conversation, and this is only really within the classroom, because again, he doesn't see a need for it outside of school as we usually understand him using his speech and signing alone.

More recently all involved with Elliot agreed that in addition to his laptop he required something more portable that could be more easily used for social conversations both inside and outside school. After assessment, it was decided that Elliot would be able to make effective use of a small device using a touch screen and a stylus pen. As we live in Wales, we were not able to make use of the scheme running in England to supply communication aids, however a friend had raised in excess of £1,100 to help us towards an aid. One of the aids tried with Elliot was a 'ruggedised' palm top (Cassiopia) with accompanying software using the same system that was already being used on his laptop. The cost was a little over £1,300 which compared favourably against other options where costs ranged between £6,000 to approx £10,000. So perhaps not too surprisingly, we decided on the palm top, and in theory we are happy with our decision! On the positive side it is relatively cheap, compact, easily portable and uses the same symbols/system that he is used to. However, on the down side the pages/grids have to be created on the home computer and then downloaded, and as we are not great on computers and software this can be a problem, e.g. just recently I created some new pages which we tried to add to others that we had already downloaded and somehow we lost the lot! Of course problems such as this mean a great deal of wasted time and effort all around, and can mean a lot of waiting for help to solve problems. If we had gone for the more expensive option pages/grids could have been created straight onto the device, which would mean less fiddling around, and in addition this would have given us the ability to create pages immediately, wherever we happen to be.

I am amazed at how much time we have spent, on Elliot's aids already, and we have certainly come to realise that ultimately the programming is largely down to parents and carers, albeit with guidance. On several occasions I have thought to myself 'great, I'll have this ready for him tomorrow' only to find that e.g. I can't create a link to another page and don't know why because I think that I am doing exactly what I have done successfully on other occasions. Then after scouring the manual to no avail, and thinking that I am going mad, I've discovered that I haven't left a space after typing a particular word, and this is the problem! Other problems have included everything freezing, and the chip failing to accommodate new grids for some mysterious reason. While I'm sure that many of you reading this will be completely computer literate, and could probably sort out such problems quickly, we can't be in such a minority and I think that many of us may experience similar problems. How effectively Elliot uses his palm top I will have to report on at a later date. We personally want him to start to use it when we are visiting friends and relatives and to use it in shops – as he is nearly 12 years old now and still very reliant on us for this type of communication. He is about to start at a new school now he is secondary age and the plan is to use it for activities outside the classroom e.g. to talk to his mates, and to tell the dinner ladies what he would like for dinner etc. At his new school there will be other children using communication aids - something that is vital in creating effective communication aid users. In addition several children also use Makaton, so we feel that this could be a very positive move.

Based on our experiences so far, I feel that while it is important to try our best to support our children's communication with all the means at our disposal, we should not be too hard on ourselves. Communication for most people is easy and efficient, but supporting it in the way many of us have to 24 hours a day is very difficult and sometimes wearing. I think that probably instead of feeling guilty at not always remembering to sign, it is better and more effective to consciously decide that at a certain time of day, you will use signing regularly. Certainly with Elliot, I used to find he was most receptive to a chat with a bedtime story, so we could talk about school, friends, etc. using signs. This also kept distractions to a minimum for both of us and meant that our hands were free. I think that it must also be very beneficial if extended family members learn to sign too. Unfortunately our families live some way off, and Elliot probably only sees them three or four times a year.

I also feel that when creating communication layouts for an aid it is important to have really good guidance, a bit of a plan before you start creating layouts and regular dedicated time set aside. I also have to say that it is great when you hear a therapist say that class situations *will* be created where your child *will* be required to use an aid every day! When this is all up and running I will write some more, in the meantime we would certainly appreciate hearing about the experiences and opinions of others on this subject.

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WDS-SG

Worster Drought Syndrome Support Group

www.wdssg.org.uk

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 January 2005

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.

Thanks for all the contributors of this issue of the newsletter especially

Professor Neville, Katie Price, Nicola Jolleff, Rebecca Harris ,Mary Rumbold

and Anita Brown.

WEB SITES THAT MAY BE OF INTEREST

http://www.ncype.org.uk/
The National Centre for Young People with Epilepsy
www.communicationmatters.org.uk/
www.makaton.org/
www.widgit.com/
www.symbolworld.org/
www.talkingpoint.org.uk/
www.btinternet.com/~black.ice/addnet/statmnt.html

REMEMBER

SEND YOUR REGISTRATION FORMS TO

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