

WORDS

The Newsletter of the Worster-Drought Syndrome Support Group

ISSUE 12

A Message from the Chairman

In life, both professional and private, we all have battles of differing sizes. Whether it be, struggling to find a plumber to service your boiler, arguing with the garage for charging too much to service the car or, for example, tackling your Local Education Authority head on.

Some of these battles are resolved by a phone call or two, or with a few letters. With the example of the LEA, as too many of you have found out, can take months and a lot of sacrifice. One of our member families' actually moved house so their child could go to a specialist school.

It is nice to "win" these little wars even though you can't help feeling that having to go through the whole process is a bit unnecessary.

However, sometimes it's the smaller victories that make all the difference. Often you don't even realise you are having a battle

until it's over. I'm referring to the little things that most families take for granted.

Our son Christopher came home from school on Tuesday this week with a letter to mummy and daddy. The writing on the outside, and indeed the inside, was instantly recognisable as that of Fiona, his full time teaching assistant, but the name at the bottom had been written by Christopher himself. For the first time he had, without prompting, written his own name in full.

With all the conflict going on in the world little victories like this really put things in perspective. I hope that you all have lots of little victories of your own.

Gavin Leech

In this issue of WORDS:

[Page 1] - Message from the Chairman

[Page 2] - News: Flora Light Challenge Feedback, SNAP, Contact a Family news, Carer's Week.

Steve Spillane

[Page 3] - Family Day June 2003 Schedule

[Page 4] - Bikes

[Page 5] - Why do children with Worster-Drought Syndrome (WDS) have difficulties with eating and drinking?

[Page 6] - Continued.

[Page 7] - CASC Roadshows.

[Page 8] - CASC Roadshow Venues, Welcome to Holland

First Workshop

WDSSG are planning to organize a small workshop at the ACE Centre - an independent charity whose role is to offer support and training for parents and professionals in the use of technology for young people in education. They are also a centre of information for people who have communication difficulties, both in speaking or writing. The staff comprises of teachers, speech therapists, occupational therapists & technical experts with extensive experience in working with the application of technology to alternative & augmentative communication.

The centre is at:

92 Windmill Road,
Headington,
Oxford
OX3 7DR.

(This workshop will only be for 1 1/2 hours.)

This workshop will take place hopefully in October 2003.

Please let me know if you are interested in the following:

Looking at certain types of software.

Discussion of signs & symbols with a speech therapist.

Learning how to use a specific speech output device.

Discussion with technical staff what computer system is appropriate for your school.

Please e-mail if you are interested at monique.lauder@btopenworld.com as there are only 6 places.

News

Flora Light Challenge Feedback

My name is Michelle Weller,. On Sunday 1st September I ran the FLORA LIGHT CHALLENGE FOR WOMEN at Hyde Park in London. I raised £282 for the research in Worster-Drought Syndrome as my nephew James who is 3yrs old was diagnosed with Worster-Drought syndrome in March 2002.

The run was very worth while doing and satisfying knowing it was for a good cause. Vanessa Butt was very helpful and I'd like to thank her for all the help she gave me by just being at the end of the phone. I hope this money helps and good luck with all the research

Yours sincerely

Michelle Weller.

Well done and many thanks to Michelle, if you would like to get involved this year and run with Michelle then please get in contact with Vanessa Butt on 01473 240761 or email vanessa@buttsco.co.uk and we will pass on the details to Michelle.

Carer's Week.

5-15 June 2003

To find out more then please look at www.carersweek.org or telephone 0207 5667608

SNAP

SNAP! Childcare (Special Needs Agency Partnership) was started by Sally Britton, an NNEB nanny with 18 years experience (12 years with special needs), and Andrew Knight, the father of a little girl who has cerebral palsy. The combined experiences provide an understanding to both nannies and parents.

We offer a nationwide service, providing nannies and carers for children and young adults who may have a range of special needs from a mild learning disability to profound and multiple disabilities.

SNAP childcare Ltd 91-93 Great Eastern Street, Shoreditch EC2A 3HZ
Tel: 020 7729 2200 Fax: 020 7729 0022
Email: snapchildcare@aol.com

Contact a Family News

Contact a family has just released a new publication for families:

"Disabled-education and disability - a parents guide to rights from nursery to University".

NB Some of the information does not apply in Scotland, Northern Ireland or Wales

To obtain a free copy then ring 0800 808 3555 or email helpline@cafamily.org.uk

This is a very clear publication well worth getting a copy.

Steve Spillane

During our family fun day last year at London Zoo, we were privileged as a committee and indeed individually, to meet many families which all are linked by Worster Drought Syndrome. Among the many faces we met were the Spillane family. I remember a conversation between my wife Jacqui and Angy in which they were swapping notes on potty training. It was a happy conversation on a special day.

With a sad heart I must tell you of the tragic death of Steve.

On behalf of the committee of the Worster Drought Syndrome Support Group, I would like to offer our sincere condolences to Angy and their two children. Our thoughts go out to them during this most difficult of times.

Gavin Leech - Chairman WDS-SG

AGM 2003 and Family Day

Sunday 22 June 2003

This year's Family Day and AGM will be very informal, so families can have fun together, have a chat, swap ideas and enable us to hold the groups AGM. All of which will take place at a wonderful venue in the Sunfield School, Clent Grove, Woodman Lane, Clent, Stourbridge West Midlands DY9 9PB. The school caters for children with severe complex learning needs.

To keep costs for the day to a minimum there will be no creche available but we have booked Dippy the Clown

Please note that parent supervision will be required at all times

Unfortunately this year we will need to ask you for a donation of £10 per family to cover some of the costs for the day

Start 11 am

Teas and coffees will be served between 11-12 pm

12 noon AGM

During the AGM there will be activities for the children,

1 pm Teddy bears picnic (Lunch)

So young and old bring your teddies and picnic lunch and join in the fun.

After lunch we will have access to:

Dippy the clown

Face Painting

Soft play area- maximum of 10 at a time

Outdoor special needs area.

Look at the animals the school is very fortunate to have animals that we can see.

Art and crafts

Walk around the grounds

Chat to others and swap ideas etc

3-4 pm

Teas and coffee

Goodbyes

We would like to thank all who have pre-registered for the event (currently 27 families). If however you have mislaid your application form, but would still like to attend please ring Mrs. Monique Lauder on 020 8428 6706 asap.

Thanks

The committee would like to thank everyone who has contributed to this newsletter, especially Professor Sheena Reilly, who some of you may remember seeing at the group's first family day.

If you have an article that you would like to be published, please contact Graham Spencer at graham.c.spencer@bt.com. Closing date for new issue is July 1st 2003

Bikes

Whizz-Kidz

Whizz-Kidz is a national children's charity with a very simple goal - to give disabled children and young people independent mobility.

By providing customised wheelchairs, tricycles and other specialised mobility equipment, Whizz-Kidz improves the quality of life of disabled children across the UK and literally lets children be children.

Experiencing the everyday things that able-bodied children often take for granted such as going to mainstream school, playing sport and being able to participate fully in family life, are vital for their future growth and development.

Whizz-Kidz is also dedicated to providing help and advice to the children and their families and raising awareness of mobility-related issues through national campaigning.

General contacts:
Phone: 0207 233 6600
Fax: 020 7233 6611
Address: 1 Warwick Row
London SW1E 5ER.

Reg. Charity No: 802872

Email addresses:

For general enquiries:
info@whizz-kidz.org.uk

For any suggestions on improving our services:
suggestions@whizz-kidz.org.uk

For application details on how to apply for mobility equipment:
kidzservices@whizz-kidz.org.uk

WRK

Supapedal trikes and quad bikes, different sizes available to suit all age ranges. Please contact

WRK
Ashfield House
School Road
St John's Fen End
Wisbech
Cambridgeshire
PE14 7SJ

Telephone 01945 880014



Martin enjoying his new bike.

Generations.

Generations aim to get kids with special needs out having fun on wheels, Our range includes pedal go-carts, trendy trikes and other easy to ride vehicles as well as passenger options.

To obtain a brochure then please contact
Generations
40 Church Gate
Loughborough
Leicester
LE11 1UE
Telephone 01509 210321

Why do children with Worster-Drought Syndrome (WDS) have difficulties with eating and drinking?

Sheena Reilly, Professor of Paediatric Speech Pathology, La Trobe University and the Royal Children's Hospital, Melbourne, Victoria, Australia.

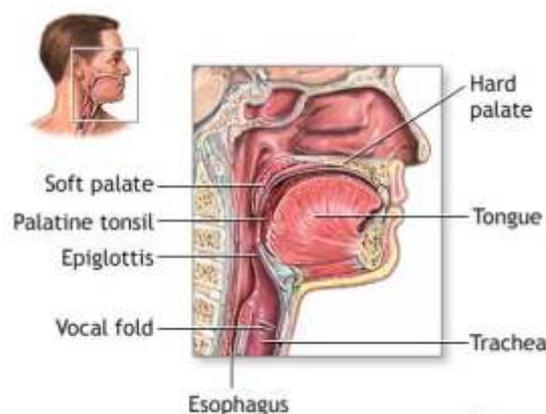
In order to answer the question posed in the title, it is first necessary to describe what happens when we eat or drink. You and I take eating and drinking for granted. We never think about the fact that every time we swallow (and we swallow hundreds of times a day) more than twenty muscles have to work together in perfect harmony to perform this very complex action. Our brain controls all the movements required for swallowing.

Before we swallow we usually prepare the food or liquid in our mouths. This is very important if you are eating solid foods like a biscuit or a piece of apple. First, you bite off a reasonable sized piece and get ready to chew it. Chewing is a complex activity and involves moving your tongue (the main muscle) from side to side, in and out and up and down. Your jaw also moves up and down and from side to side, as well as moving in a circular motion. Your lips work hard to help keep the food inside the mouth, so you don't spill the food. All of these movements have to be coordinated so that the food is prepared for swallowing. Next time you are chewing something solid, have a think about what your tongue, lips and jaw are doing.

Once you've crunched up the food you form it into a ball (you use your saliva to help with this) and place that ball, or bolus, of food on the middle of the tongue in preparation for swallowing. The food is moved backwards by the tongue, using a wave-like motion, and propelled into the throat (pharynx). This is the first part of the swallow. Just as this is happening, the soft palate (that's the dangly bit you can see at the

back of the throat) has to lift up very quickly and close off the entrance to the nose. This is important, because it stops food or liquid entering the nose which, as you can imagine, is very unpleasant.

Food and liquid then travel rather quickly with gravity and heads downwards ready to enter the food pipe (known as the oesophagus). This is a long pipe with a valve at the top and the bottom. First, the valve at the entrance to the oesophageus (the cricopharyngeal sphincter) has to open or relax to allow food in. Then the food is moved down the food pipe with wave-like muscle movements. Once the food reaches the bottom of the food pipe there is another valve that needs to open to allow the food to enter the stomach. Once food has passed through, the valve closes up, to stop any of the stomach contents coming back up into the oesophagus.



Picture from www.nlm.nih.gov/medlineplus/ency/article/003115.htm ADAM

Children with WDS can have difficulty with all or some of these stages and each will be discussed in turn. Three stages are discussed: the oral stage (the mouth), the pharyngeal stage (the throat) and the oesophageal stage (the food pipe).

Oral stage

Children can experience a range of difficulties with the oral stage. Many of these occur because of a limited range of tongue, lip and jaw movements. It is particularly the limitations with tongue movements that prevent many children from being able to take a normal diet. Managing solid foods requires munching or chewing and the ability to move food around the mouth, its particularly important to be able to place food between the teeth for chewing. Unfortunately many children with WDS do not have lateral (that is, side to side) movements of the tongue. Their jaw movements may also be limited, for example, they may have limited up and down movements (making opening and closing movements) and not be able to perform the lateral (side to side) or circular movements that are necessary. The tongue probably plays the most important role in a child's ability to suck, chew and swallow. Thus, an absence of a full range of tongue movements, or limited tongue movements, can result in quite significant difficulties in the oral stage. As a consequence, drooling and spillage of food may occur. Many parents ask why children have particular difficulties with liquids, as this would appear to be an easier texture for them to swallow. However, far great tongue control is required for drinking liquids, and this control needs to be more precisely and rapidly coordinated than for thicker textures.

Pharyngeal stage

There are a number of problems that can occur once the food enters the pharynx, or the throat. Many children have difficulty

initiating a swallow, and the muscles that progress the food and liquid through the pharynx can sometimes be less effective. Therefore, food may not be completely cleared. The valve (cricopharyngeal sphincter) at the top of the food pipe may also not open readily and relax when required. However, one of the biggest problems at this level is inadequate protection of the airway. If you look at the diagram you'll see that the throat or pharynx is a common pathway for food and liquid and also the air that we breathe. Many of us consider that this is a big design fault in an otherwise amazing body. This is because the airway requires constant protection in order to prevent food or liquid going the wrong way thereby entering the airway rather than the oesophagus. For most of us, it is a rare event to cough or choke. However, imagine that some of the twenty muscles I mentioned earlier aren't working well or that they are poorly coordinated. You only need a few things to go wrong in this very complex process to start having some difficulties protecting their airway.

When food and drink does go the wrong way and end up in the airway its called aspiration. Your speech pathologist or paediatrician may have talked about different tests that they might use to assess whether aspiration is occurring, and one of the most common of these is a videofluoroscopy swallowing examination, or a barium swallow. This is a moving x-ray that can confirm whether aspiration may be occurring.

Oesophageal stage

There are many difficulties that can occur with the oesophageal stage. The two most common ones are gastro-oesophageal reflux, and oesophageal dysmotility. Gastro-oesophageal reflux occurs when contents of the stomach come back and

wash up into the oesophagus. Because the stomach contains acid, this can be very unpleasant and painful. The acid can, of course, also do some damage to the lining of the oesophagus and cause heartburn (anyone who has experienced heartburn knows it is uncomfortable). Sometimes the refluxed stomach contents stays just in the oesophagus, but it can also travel into the pharynx and/or the mouth. In some children this can cause vomiting or regurgitation (that is, spitting up or positing small amounts of food or liquid).

There are a number of ways in which Gastro-oesophageal reflux can be treated. The first treatments usually consist of a combination of medications to try and reduce the symptoms and the stomach acid. However, if the problem is very severe, surgery may be required.

Oesophageal dysmotility occurs when the muscles in the oesophagus (food pipe) do not move the food and liquid effectively through the oesophagus. This can be uncomfortable for the child, and it may feel like food is stuck.

Summary

Not all children with WDS have eating and drinking difficulties, and certainly not all will have problems with all of the three stages outlined above. However, these difficulties may affect:

- the type of food your child can eat for example they may have particular difficulties with more solid foods or with liquids. Remember also that some foods are much harder to control than others.
- the amount of food that children eat for example, if you have pain or discomfort as a result of reflux (or, for other reason) your appetite and desire to eat may be reduced. Some children also learn to associate eating and

drinking with pain or discomfort.

- the speed at your child can eat or drink - mealtimes might be slower.

Any difficulties eating and drinking, can impact on whether children perceive eating or drinking to be a pleasurable experience. The most important consequences of difficulties eating and drinking in children with WDS are poor growth and the development of respiratory problems. Poor growth may occur because the child is not able to take in enough calories to maintain a satisfactory growth pattern. Children who vomit as a result of gastro-oesophageal reflux, may be losing calories. Respiratory problems can develop when children are at risk of aspiration (that is, food and liquid are going down the wrong way, and entering the airway). The lungs are definitely not designed to have any foreign bodies (food and liquid) entering. Therefore, chest infections may develop, and over time lung damage may occur, resulting in recurrent pneumonias.

In children with WDS we aim to prevent, where possible, these problems from occurring. In the first instance, we want to maximise the children's nutritional intake so that they can achieve a satisfactory growth potential. This can mean helping to supplement oral intake using some of the commercially available supplements, or manipulating diet (that basically means feeding them all the fattening things you wish you could eat!). In addition, we also aim to prevent, where possible, or reduce the likelihood of aspiration occurring during eating and drinking. In order to achieve this, sometimes we have to modify the type of food the children eat, or the way in which they eat. In severe cases it may be necessary to use tubes to assist with feeding.

CASC Road Shows

What are the CASC Road Shows?

CASC Road Shows provide an overview and an update of specialised communication aid technology for use by people with severe speech and communication impairment and writing difficulties. Road Shows are held throughout the year in UK and Ireland.

A CASC Road Show is a valuable opportunity to learn about communication aid technology 'straight from the horse's mouth'. A number of the UK's leading manufacturers and suppliers of adaptive devices and voice output communication aids will demonstrate and provide 'mini-master classes' on their latest products. At least one supplier will be represented by a communication aid user who will demonstrate and present the user's perspective. There will be opportunities for questions and hands-on trial of systems, and lots of valuable handouts and literature to pick up.

Each Road Show has a full day's programme delegates will attend eight workshop sessions in which the companies will present and demonstrate devices such as:

- Light Tech (e.g. Big Mack, Talking Buddy Buttons, Step-by-step communicators)
- Mini digitised speech output (e.g. Barry Boxes, MessageMate)
- Digitised and Synthetic speech output (e.g. AlphaTalker, Cameleon, CV, DeltaTalker, DynaMyte, DynaVox, Eclipse, Lightwriter, Orac, Vanguard)
- Computer software (e.g. Speaking Dynamically, Words+, Clicker)
- Mounting systems, and more...

If you are interested in seeing a particular device or piece of software, please ring the telephone number below to make sure it will be presented on the day. Depending on the venue, attendance is free or there is a small charge. Buffet lunch and refreshments are sponsored by CASC. In either case, you must book a place in advance please refer to the diary below for the telephone number to

contact.

If you are interested in hosting a CASC Road Show in your area, contact **Communication Matters** for more information.

Who is the Road Show for?

- People new to the field of Augmentative and Alternative Communication and voice output technology
- Professionals specialising in this field who want to update their knowledge technology changes fast!
- Everyone with an interest in communication technology
- Anyone who works with children or adults with severe speech, language or communication difficulties and are in need of some special support with communication

Who will be presenting?

The presenters will be representatives from various companies that manufacture or supply voice output communication aids, including: Cambridge Adaptive Communication, Crick Software, Don Johnston, Easiaids, Hearing Products, Liberator, Morphonics, Photon Technologies, Prentke Romich International, QED 2000, Richard Hill & Associates, Ritchie Electronics, Sensory Software, Sunrise Medical/Dynavox, Techcess, Toby Churchill, Widgit Software, and others. Please note that companies attending will vary with venue.

Road Shows Diary: 2003

To book a place, please contact **Communication Matters** by email or phone and give your name, full address with postcode and contact telephone number - you will receive an acknowledgement of your booking within a few days. All Road Shows are free of charge, except where otherwise stated.

See next page for dates of venues and contact details. 

CASC Roadshow Venues

13 May**Ashford,
Kent**

Stour Centre, Tannery Lane, Ashford, Kent,
TN23 1PL

Cost:

£10 payable to "Find a Voice"

20 May**Wycombe,
Bucks**

Postgraduate Education Centre, Wycombe
Hospital, Queen Alexandra Road, High
Wycombe Buckinghamshire HP11 2TT

21 May**Bristol**

Paediatric Communication Aids Service,
Claremont School, Henleaze Park, Westbury
on Trym, Bristol BS9 4LR

25 June**Stourbridge**

Sunfield School, Clent, Stourbridge DY9 9PB

Cost:

£5 payable to "Sunfield PDC"

30 June**Portsmouth**

Futcher School, Drayton Lane, Drayton,
Portsmouth PO6 1HG

All Road Shows will start at 9.30am and finish at 3.00pm (registration 9.00-9.30am), unless otherwise stated. There are usually 6 sessions during the day. In each session, all the companies present parallel workshops and participants can choose to attend any workshop. Each workshop is repeated in each session throughout the day.

Contact Details:

admin@communicationmatters.co.uk

Tel: 0845 456 8211

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability to try and help people who have not shared that unique experience to understand it - to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy, you buy a bunch of guide books, make wonderful plans, the Coliseum, Michael Angelo's David, the Gondolas in Venice, you may even learn some handy phrases in Italian, it's all very exciting.

After months of eager anticipation, the day finally arrives, you pack your bags and off you go, several hours later the plane lands, a flight attendant comes in and says, "Welcome to Holland".

"Holland" you say, "What do you mean Holland? I signed up for Italy, all my life I've dreamed of going to Italy".

But there's been a change of flight plan, they've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease, it's just a different place.

So you must go out and buy new guidebooks and you must learn a whole new language and you meet a whole new group of people who you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy but after you've been there for a while and you catch your breath, you look around you and notice that Holland has windmills,

Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy and they're bragging about what a wonderful time they had there. For the rest of your life you will say "Yes, that's where I was supposed to go, that's what I had planned". And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, very lovely things about Holland.

Emily Pearl Kingsley