SPRING 2008 ISSUE 223

link

The magazine for people with hydrocephalus and spina bifida

New ASBAH website

see more on pages 6 and 7

INSIDE THIS ISSUE

- Pigeon show fundraiser
- Recycle your mobile phone
- Support and relationships
- NPH supplement
- News round-up
- Hydrocephalus Action update
- Transition Clinic feature

association for
spina bifida
hydrocephalus
ability beyond disability
TM

Sponsor a balloon

You could be up, up and hopefully far away as a winning sponsor in one of our annual ASBAH balloon races.

For a small cost, which goes to help people with spina bifida and hydrocephalus, you can back a balloon to travel the furthest in one of our 10 races around the country. The winning balloon will win its sponsor a case of champagne.

But you'd better have the wind at your backs – previous winners' balloons have made it to Germany, Belgium and the Netherlands.

ASBAH holds 10 races a year. The next three races in 2008 are as follows:

May Day	**1 May 2008**
Mid Summer	**2 June 2008**
St Swithins	**14 July 2008**

For more information call our telephone fundraising team on 01733 421334

link

the lifestyle magazine for people with hydrocephalus and spina bifida

Subscription Form

Link is published quarterly
(Winter, Spring, Summer and Autumn)

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Association for Spina Bifida and Hydrocephalus • Registered charity number 249338

Gill Winfield writes

It is always good to start the New Year on a high and it has certainly been an exciting and busy time for ASBAH as we frantically put together our new website in time for the Spring launch.

We have known for some time that the website needed a serious revamp, with a brighter look and easy to negotiate sections.

It has taken the designers a lot of time and effort, but at last everything came together, as you'll see from the special feature on pages 6 and 7. The website will continually be updated to make sure it is relevant to you.

Also in this issue is our special Normal Pressure Hydrocephalus (NPH) supplement (page 13), covering all aspects of the condition from causes through to treatment.

On page 19 you'll find a feature about how a disabled child can put strain on its parents' relationship – we'd especially like to hear about your thoughts and experiences on this subject.

Our Days in the life of… subject this time (page 30) is popular *Link* columnist Linda Corbett, who reveals a little more about her daily life.

There's also the regular news, education and Your Voice sections, plus fundraising stories.

So there's plenty to read and discuss. Please get in touch with your comments and news – it's always a pleasure to hear from you.

Gill Winfield
Marketing and Communications Manager
gillw@asbah.org

(Cover picture: Abbeygail White with her children Megan, Oliver and Francesca at an ASBAH family weekend)

Patron:
HRH The Duchess of Gloucester GCVO

President: Jeffrey Tate CBE

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life

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Information Sheets

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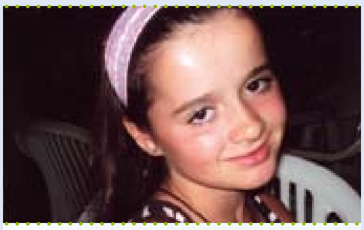
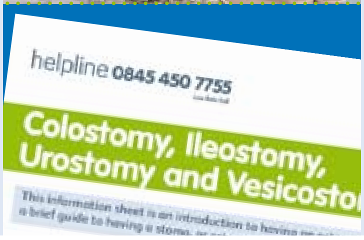




helpline 0845 450 7755
Colostomy, Ileostomy, Urostomy and Vesicosto
This information sheet is an introduction to having
a brief guide to having a stoma

Preventing NTDs – can you help?

ASBAH is hoping women will come forward to take part in a clinical trial of a vitamin which may help reduce the risk of Neural Tube Defect (NTD) pregnancies.

It has long been known that folic acid reduces the risk of spina bifida but now scientists believe that a lack of the vitamin inositol can also cause the baby to develop an NTD such as spina bifida or even anencephaly (where the brain is largely absent).

There is already some evidence that inositol can prevent NTDs and ASBAH is keen to support a new study being funded by the Medical Research Council.

ASBAH has been asked to appeal for women who have experienced an NTD pregnancy to join the study and perhaps take the vitamin inositol (as well as folic acid), if they are planning another pregnancy.

As many women as possible are needed in the study to give a meaningful result.

No dangers or side-effects of inositol are known. It has been used in high doses to treat other conditions and is naturally widespread in many foods.

No problems have been found and it has been used safely in many other research studies with no ill effects.

The research study will run through 2008 at the Institute of Child Health, London.

Anyone wishing to know more, or considering taking part, should contact Rosemary Batchelor, ASBAH Senior Medical Adviser, via the helpline on 0845 450 7755.

You can also get more information from the study web site at: ***www.pontistudy.ich.ucl.ac.uk***

You can contact the clinical trial co-ordinator Louise Thomasson on 07948 118506 ***ponti@ich.ucl.ac.uk***

What is Inositol?

Louise Thomasson, clinical trial co-ordinator for the Inositol study explains more about this little known vitamin.

"Inositol is classified as one of the B vitamin complex (often referred to as B8), although it isn't strictly a vitamin as it can be synthesized by the body.

It is a carbohydrate that closely resembles glucose in structure and is found in many foods, including cereals (especially those with high bran content), nuts, beans, and fruit such as cantaloupe melons and oranges.

Human adults generally consume approximately 1g of Inositol each day.

It is a crucial constituent of living cells and participates in several physiological functions.

As well as being found to play beneficial roles in fertility and fetal development, myo-Inositol has been used in the treatment of liver disease, depression and respiratory distress syndrome (found in premature babies due to poor lung development) among others.

Reports of NTD pregnancies recurring in a family despite high dose folate intake argue strongly that a proportion of NTD cases may be fundamentally resistant to folate.

It has previously been reported that a small number of pregnant women who had one or more previous NTD pregnancies were given Inositol and went on to have unaffected babies."

Symposium for professionals

ASBAH is organising a small symposium aimed at senior doctors and surgeons on the management of diagnosis of neural tube defects (NTDs) in pregnancy.

The event, for professionals only, will be held at the Royal College of Obstetricians and Gynaecologists in London on 19 May.

The group will look at how we can improve the support for pregnant women/parents who are given a diagnosis of fetal impairment.

The symposium will offer an opportunity to air the approaches used and difficulties encountered by various specialists.

The meeting aims to see what is happening at different centres around the country and to try to agree standards and perhaps guidelines, for Royal Colleges, to help professionals work together to give the best possible service to patients at a distressing time.

Stop press

Further delay on folic decision

As Link goes to press we have received the disappointing news that there will be further delays before a final decision is made on whether flour should be fortified with folic acid.

The Scientific Advisory Committee on Nutrition (SACN) had been asked to consider whether recent research papers should affect their recommendation on fortification. Following a meeting in February SACN decided that although there was insufficient evidence to warrant any change to their original recommendation, they would defer agreeing final advice on folic acid and risk of cancer until the results of more data from ongoing trials could be assessed. This means that there will be no further progress until mid 2009 at the earliest.

Support group welcomes all

A Dunstable-based support group is still going strong after an impressive ten years.

The group, which meets up on the second Monday of every month, welcomes anyone – children included - who have spina bifida and/or hydrocephalus.

Lorraine Watson from the Herts and South Beds ASBAH local association, said: "The group was started about ten years ago by a previous adviser, Sue Davis.

"We don't have a membership as such as it is just a drop in group. There are about ten regulars but new faces are always welcome.

"Sometimes someone comes to give a talk or we just have a general chit chat amongst ourselves… and of course there's always tea and biscuits. John Richards, our area adviser, also attends most of our meetings."

The group meets on the second Monday of every month from 1pm to 3pm at The Disability Resource Centre, Poynters Road, Dunstable.

Lorraine added: "Please come whenever you can and stay for as long as you can."

For more information about the support group call Valerie Bottoms on 01582 757745.

FREE tickets

Don't miss out on your chance to snap up free tickets for the latest *Beyond the Boundaries Live* exhibition which showcases dozens of ways disabled people can live their lives to the full.

The event, on 25-26 July at the Kent Showground, Kent, is expected to attract hundreds keen to become involved with many different activities.

Central to the event is the 'Can Do' attitude rather than accepting second best.

Now in its second year, *Beyond Boundaries Live* will be pushing the boundaries even further, offering even more challenging activities from sports, the arts, holidays, work and recruitment among others.

It will also host inspirational talks from disabled celebrities and people who have achieved amazing feats of endeavour.

For more information about registering for free tickets and the full programme of events check out ***www.beyondboundarieslive.co.uk***

19th IF conference

Portugal will host the 19th IF World Conference on Spina Bifida and Hydrocephalus this summer.

The event, organised by the International Federation for Spina Bifida and Hydrocephalus (IFSBH), takes place in sunny Lisbon from 6 – 9 June.

The theme of this year's conference is 'Drawing Smiles – towards adulthood', and will touch on subjects including transition, growing up with these conditions and quality of life.

For more information check out ***www.spina-bifida2008.org*** or ***www.ifglobal.org***

Grants help students

An established charity offers grants to disabled students to help them complete further education or training.

The Snowdon Award Scheme, which has been running since 1981, offers around 100 grants each year to physically disabled and sensory impaired students studying in the UK – in further or higher education or those training towards employment.

The Grants, which range from £250 to £2,000, help cover the additional costs that these students incur as a result of their disability, where available statutory awards do not cover them.

These costs include vital support such as personal carers, people to take notes, computers, specialist software, wheelchairs or special accommodation and equipment.

Applications are considered by an independent selection panel, made up of both disabled and non-disabled people who have knowledge and understanding of a wide range of disabilities.

The charity was set up by Lord Snowdon, who saw that many physically disabled young people were being denied the chance to pursue further education or training because of extra costs incurred as a direct result of their disability.

During 1981, the first International Year of Disabled People, he devised a scheme that would help and encourage these people to take their place on a more equal footing with their contemporaries.

To learn more about the scheme go to ***www.snowdonawardscheme.org.uk*** or call 01403 211252 for more information.

It's been many months in the planning, but ASBAH's vibrant new website goes live this Spring.

Main homepage

association for
spina bifida
hydrocephalus
ability beyond disability

Viewing Options Donate Publications

Search this site

Helpline: 0845 450 7755

Home About ASBAH Spina Bifida Hydrocephalus Folic Acid Get Involved ASBAH Community Professional

Hydrocephalus

The term 'Hydrocephalus' is derived from two Greek words meaning 'water in the head'. In fact, the 'water' is cerebrospinal fluid (CSF), a clear liquid which is produced all the time in the cavities or ventricles inside the brain.

Read more

Register Here

Login

Shop online with:
The ASBAH Webshop
OPEN

Related Links:

Inositol Survey
Scientists are appealing for women who have experienced a neural tube defect pregnancy to take part in an important new study.

Events
Take a look at what events are happening near you.

Publications
ASBAH offer a range of publications that focus on issues that may affect people with Spina Bifida and or Hydrocephalus.

Tell us your story

Information Sheets

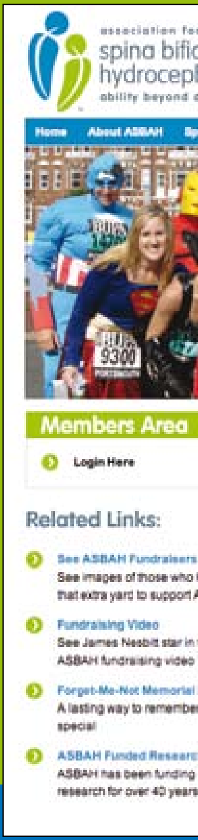
A number of information sheets have been produced by specialists to help answer any questions you may have.

Hydrocephalus Information
Spina Bifida Information
Lifestyle Information
Education Information

Fundraising

Popular actor James Nesbitt helps to explain some of the issues surrounding Spina Bifida and

Get Involved: sub



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Related Links:

See ASBAH Fundraisers
See images of those who
that extra yard to support A

Fundraising Video
See James Nesbitt star in
ASBAH fundraising video

Forget-Me-Not Memorial
A lasting way to remembe
special

ASBAH Funded Researc
ASBAH has been funding
research for over 40 years

Check out our new websit

We've been keen to establish a new website that would build on the success of our previous site – which received an average of 20,000 visits each month – and respond to the rapidly changing developments of the worldwide web.

While our old website, which was launched in 2004 did a good job, we felt it was time to brighten it up and make it easier to negotiate. The site also has various viewing options for the visually impaired.

It's been a frantic few months to get ready for the Spring launch, but I'm sure everyone will agree it has been worth the effort.

The home page on the new-look ASBAH site features a list of news items, with the main article changing frequently to help identify new features within the site.

There are now separate sections for Spina Bifida, Hydrocephalus and Folic Acid, plus an ASBAH Community area which includes a wide range of case studies on a variety of issues.

The fundraising area, now called 'Get Involved', leads to dedicated areas for corporate and individual supporters, so have a look and please support us by buying a balloon or by sending a donation through our new e-secure payments and donations area.

The Information Sheet area is also clearly separated into the four main issues – Spina Bifida, Hydrocephalus, Lifestyle and Education Information – to help users find the material they need quickly and easily.

"Coloplast are delighted to support such a worthwhile charity as ASBAH and are excited about the new website and all it will have to offer for ASBAH and its members."
Sue Frost, Medical Product Manager (Bowel Management)
Coloplast Limited

"Codman believes the Hydrocephalus Action website will lead to better and more precise information being passed to the patient and their families, allowing them to fully understand the conditions and outcomes represented.

"We hope our collaboration will help bring new innovative products to the market, aiding surgeons to improve patient outcomes even further."
Edward Lamb,
Codman UK Country Manager

"This is an exciting and important step forward for ASBAH. Our website is already recognised internationally.

We have relaunched the website to make it easier for visitors to navigate and find what they need.

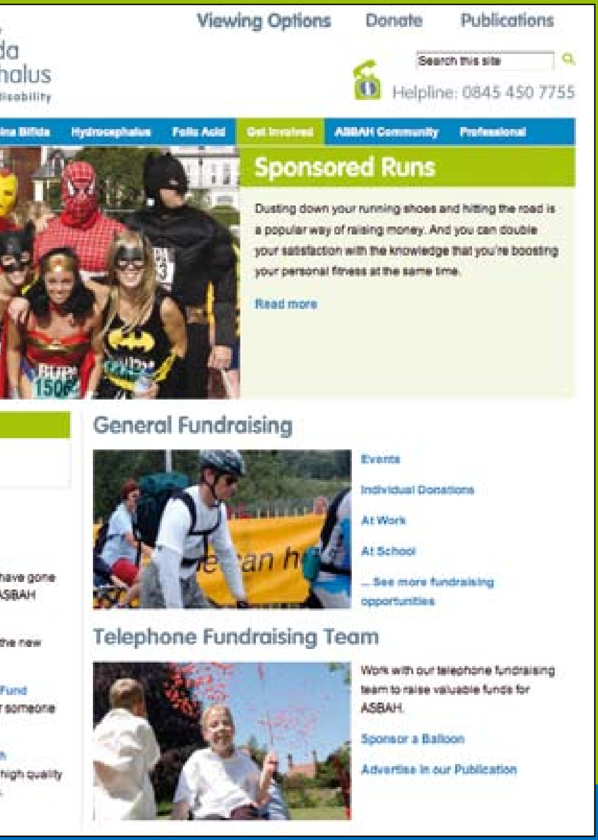
A huge amount of information is there, but it had been repeatedly added to, over several years, so it needed redesigning to keep it accessible as well as attractive. We think we've achieved this.

I hope that many people will take a look and give their comments on the content as we need to make sure we do the best job possible.

The internet is so important today to people with spina bifida and /or hydrocephalus that we're determined to make ASBAH's website serve everyone's needs."

Andrew Russell
ASBAH Chief Executive

-page



Sponsored Runs

Dusting down your running shoes and hitting the road is a popular way of raising money. And you can double your satisfaction with the knowledge that you're boosting your personal fitness at the same time.

Read more

General Fundraising

Events

Individual Donations

At Work

At School

... See more fundraising opportunities

Telephone Fundraising Team

Work with our telephone fundraising team to raise valuable funds for ASBAH.

Sponsor a Balloon

Advertise in our Publication

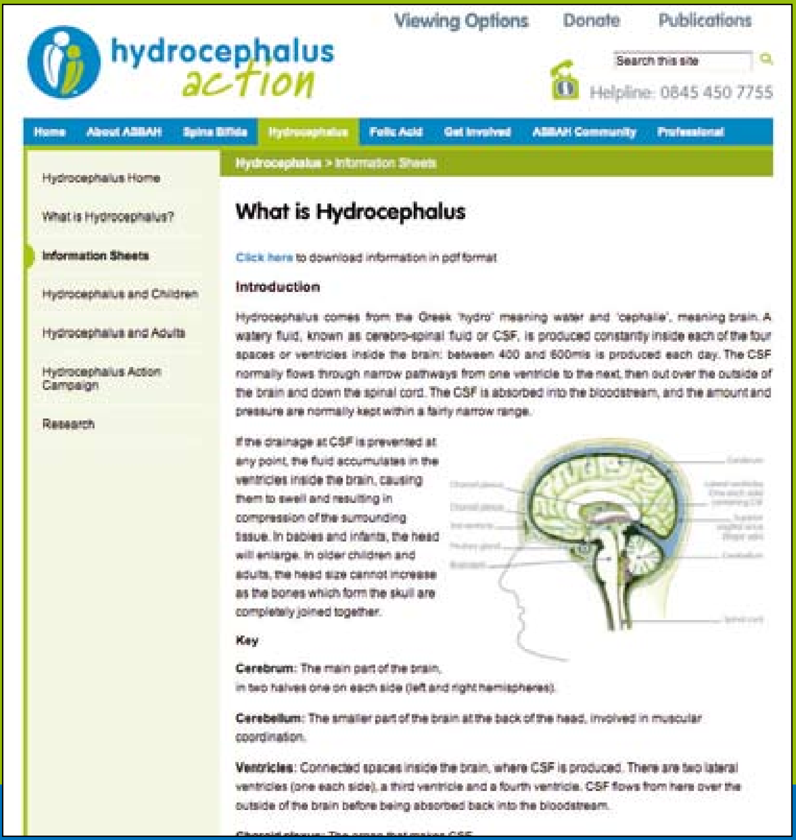
have gone
ASBAH

the new

Fund
someone

high quality

General contents page



What is Hydrocephalus

Click here to download information in pdf format

Introduction

Hydrocephalus comes from the Greek 'hydro' meaning water and 'cephalie', meaning brain. A watery fluid, known as cerebro-spinal fluid or CSF, is produced constantly inside each of the four spaces or ventricles inside the brain: between 400 and 600mls is produced each day. The CSF normally flows through narrow pathways from one ventricle to the next, then out over the outside of the brain and down the spinal cord. The CSF is absorbed into the bloodstream, and the amount and pressure are normally kept within a fairly narrow range.

If the drainage at CSF is prevented at any point, the fluid accumulates in the ventricles inside the brain, causing them to swell and resulting in compression of the surrounding tissue. In babies and infants, the head will enlarge. In older children and adults, the head size cannot increase as the bones which form the skull are completely joined together.

Key

Cerebrum: The main part of the brain, in two halves one on each side (left and right hemispheres).

Cerebellum: The smaller part of the brain at the back of the head, involved in muscular coordination.

Ventricles: Connected spaces inside the brain, where CSF is produced. There are two lateral ventricles (one each side), a third ventricle and a fourth ventricle. CSF flows from here over the outside of the brain before being absorbed back into the bloodstream.

e

Shop online via the ASBAH website… you'll add pounds to our funds

The launch of the new ASBAH website has created many exciting new fundraising opportunities.

If you shop via the internet then you may be able to add cash to the ASBAH coffers simply by using the ASBAH Webshop link featured on the ASBAH home page.

Just click and you will be able to access over 150 of the most well known retailers in the UK.

From Asda to Woolworths; Boots to Tesco; Currys to Sainsburys and dozens more – all through the ASBAH Webshop.

Every purchase made through the ASBAH Webshop is automatically identified as an ASBAH purchase and the charity receives a donation of between 3% and 10% (depending on the product) of the purchase price.

For example: £30 worth of groceries bought this way at Tesco would generate about £1.50p to ASBAH and a £500 TV from John Lewis could generate as much as £50 to the charity… without any extra cost or effort to you, the shopper.

Colin Roberts, ASBAH's Director of Fundraising said: "It's a real win win situation. Anyone shopping this way can make great personal savings by making use of the special offers and discounts given to internet shoppers and, at the same time, generate significant funds for ASBAH.

"If you, your family, friends and colleagues shop using the Internet in this way, ASBAH will benefit greatly."

So spread the word - shopping online with ASBAH has arrived. Go via the ASBAH Webshop and help ASBAH while you shop.

KEY POINT

- The new ASBAH website is now easier to use
- It includes a great new way to support ASBAH. Log on to *www.asbah.org*

Professional area

One new innovation to the website will be the Professional Area, open only to health professionals who register with ASBAH.

To begin with the section will deal purely with hydrocephalus, although it is hoped a spina bifida section will be up and running next year.

The Professional Area aims to become a recognised reference area for health professionals throughout the world who deal with patients with hydrocephalus.

Users will be able to upload and download medical teaching materials, including videos, animations and information sheets.

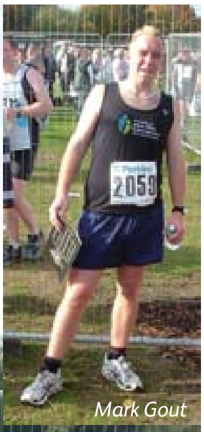
They can also access information for research or download material suitable for patients and their carers.

Another positive is that the area will put professionals in touch with each other or they can post questions for others to answer.

The area will be divided into News,, a Reference Library, Questions & Answers, New Products & Conferences and Events, to help keep professionals up-to-date with hydrocephalus news from around the world.

The Great Eastern Run gets Greater and Greater

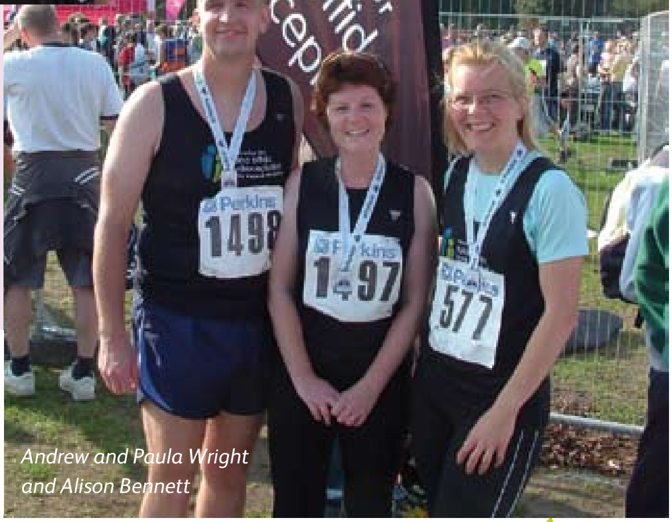

Shelly and Michael Bullard


Mark Gout

The 2007 Great Eastern Run was the most successful ever. Personal bests were smashed and nearly £800 was raised for ASBAH as the runners pounded through 13 miles of streets in Peterborough.

Five people took part to raise money for ASBAH: Michael Bullard (husband of ASBAH's Community Fundraiser Shelly Bullard); Andrew and Paula Wright (regular fundraisers whose daughter Katie has hydrocephalus); Mark Gout and Alison Bennett.

A huge thank you to everyone that took part and raised money for ASBAH.


Andrew and Paula Wright and Alison Bennett

Intrepid four hit the road for ASBAH

Congratulations and thanks go to the Gathering Motorcycling Club from Holyhead in North Wales.

It recently donated a wonderful £1,062 raised by a sponsored ride from Land's End to John O'Groats.

The group has been fundraising for ASBAH for ten years in memory of Alison Calvert who used to attend the club with her sister.

From left: Phil Smith, Sarah Davies, Bethan and Carl Hunt

Alison, who had spina bifida and hydrocephalus, died when she was 18, and the Club has held an annual fundraiser ever since.

The four riders who completed the mammoth 860-mile journey were Carl and Bethan Hunt, Phil Smith and partner Sarah Davies.

Phil told *Link*: "We travelled from Holyhead to Scotland the day before the run, leaving John O' Groats at 5.30am on a cold windy and wet morning. As we started to cross the highlands the weather started to improve.

"Due to the fuel tank size we had to re-fill every 120 miles and also had to carry a spare gallon in case we ran out. In total we stopped eight times for quick refills.

"We arrived at Land's End at 5.17pm - but the journey didn't end there – we still had to find a hotel for the night.

"We eventually got a room in Plymouth at 11.45pm, quite some miles away, which made it a very long day."

Including the travel to and from Holyhead, the intrepid four covered 2,000 miles in three days – and all to raise funds for ASBAH. We can't thank you enough.

GREAT MANCHESTER, NORTH AND SOUTH RUNS
'Places Available'

RUN for ASBAH

ASBAH is a registered charity that provides advice and support for over 15,000 babies, children and adults with spina bifida and hydrocephalus.

We need your help so we can continue to promote awareness, help families and carry out vital research.

For sponsor forms, please contact:
Ian Morley, ASBAH, 42 Park Road,
Peterborough PE1 2UQ
Tel: 01733 421328
Email: ianm@asbah.org
www.asbah.org

association for
spina bifida
hydrocephalus
ability beyond disability

Registered charity no. 249338

STAR supporters

Link's Star Supporter this time is the Abbey branch manager Sue Geraghty along with The Abbey Charitable Trust, whose £2,500 donation has funded the much-needed Money Management leaflet.

The new leaflet, launched in February, is aimed at people with spina bifida and/or hydrocephalus who are thinking about becoming financially independent for the first time.

Abbey
PART OF THE SANTANDER GROUP

ASBAH's £2,500 donation was made as part of the 150th anniversary celebrations of the Abbey building society.

To mark the anniversary Abbey's parent company, asked its employees to nominate their favourite charities to receive one of 150 grants of £2,500 each from their Charitable Trust.

Sue Geraghty, manager of the Abbey branch in Romsey, Hampshire, is a long term supporter of ASBAH and so she nominated us as her favourite charity. Sue has been fundraising for ASBAH since 2005 when her neighbour's granddaughter was born with spina bifida.

Over the last three years Sue and the Sidecar Motorcross Association, of which she is a member, have helped to raise over £1,380 through various events, including a dinner dance with an auction and raffle.

These totals were generously match funded by Abbey Charitable Trust, doubling Sue's donations. And by choosing us as her favourite charity ASBAH also benefited from the £2,500 150th anniversary grant.

Abbey Charitable Trust was established in 1990 and to date has donated over £20 million to charities in the UK.

The organisation is committed to supporting local communities and disadvantaged people, particularly in those areas where Abbey has a significant presence.

> **We are very grateful to Abbey and Sue Geraghty for their help.**

They fund projects based on three priorities: education and training; financial advice and community regeneration

Last year it spent more than £817,000 on education and training, £390,000 on financial advice and £248,000 on community regeneration projects.

Helen Dow, project co-ordinator said 'We are very grateful to Abbey and Sue Geraghty for their help."

helpline 0845 450 7755

Money management

Budgeting

Abbey

Keeping on top of the bills

The six-page Money Management leaflet, was launched in February.

The comprehensive guide, written by a youth finance specialist, is packed with helpful advice covering all aspects of handling your cash. It includes everything that you need to know about budgeting and also provides a wealth of resources for more information.

ASBAH's Director of Services Mary Malcolm said: "Moving out of the family home is exciting, but, alongside freedom comes new responsibilities.

"Gone are the free meals, free lifts and the cheap accommodation. Not only do you have to do all your own washing; you'll also need to learn how to pay for your new-found independence too.

"We knew there was a real need for a financial information leaflet and thanks to the Abbey Charitable Trust we have been able to put Money Management together.

"Many people have been involved with its production, to make sure that nothing was missed out, and I would like to thank everyone for their invaluable help."

You can download a copy of the Money Management information leaflet from the ASBAH website *www.asbah.org*

To request a copy call the Helpline on 0845 450 7755.

Fighting the Fear for ASBAH

Rachael East has put her bravery to the test after taking part in an action packed, adrenaline filled event, to raise money for ASBAH.

Back in October Rachael and friend David Shaw took part in the Awesome Foursome Experience, a one day event held at the Magna Science Adventure Centre in Sheffield and organised through online company Bungee Club UK. The event gave Rachael the chance to have a go at abseiling, zip lining, parachute descending and indoor bungee jumping, raising £700.

In April, Rachael plans to put her nerves to the test once again to take part in a sponsored sky dive with a colleague, Kim Smith. It is estimated that through sponsorship from Bridgestones Limited, for whom Rachael works, and The Debt Angel, over £1,500 will be raised for ASBAH.

Rachael, who's mum has hydrocephalus, said: "I really enjoyed taking part in the Awesome Foursome Experience. Even though I was completely terrified to begin with it was excellent fun. I'm so pleased that I did it and managed to raise a substantial amount of money for a charity that has helped my family. I'm now looking forward to my sky diving challenge and would like to thank Bridgestones for sponsoring me, their contribution will really boost the total figure."

> I'm so pleased that I managed to raise a substantial amount of money for a charity that has helped my family.

Emily inspires Church to donate

Youngster Emily Speirs has helped and inspired her church to donate more than £3,000 to ASBAH.

Father Brian Kealey and parishioners of Christ the King and St Teresa's Churches in Burnley, decided to donate money to ASBAH after watching the latest series of a Channel 4 programme called 'Born To Be Different'.

The programme featured Emily, 7, from Burnley, demonstrating her determined character in coping with day-to-day life.

Half the proceeds of Christ the King's Christmas Fair were designated to the ASBAH fund and the Christmas collections at both churches were also donated. Emily added to the final amount by making and selling cakes at church.

When Emily's parents, Rachael and Richard Speirs, found out she had the condition during their 20-week scan they were naturally anxious. But, after contacting ASBAH, they received a visit from an adviser who provided help, information and guidance to the family. Since then, ASBAH has helped the family to manage Emily's spina bifida.

Emily herself presented the cheque for £3,100 on behalf of the parishioners, to Joan Pheasant, ASBAH's Northern Region Manager. Also present was Mary Whitham representing St Teresa's Church.

Emily, who has a four-year-old brother, Jacob, attends Christ the King RC Primary School.

Wheels of fortune

Eleven year old Gwen Angharad Roberts has raised more than £3,000 for ASBAH by racing around her school running track.

Gwen, who has spina bifida and uses a wheelchair, completed ten laps of the 150m track in a speedy 26 minutes. In the months leading up to the challenge, her preparation clocked up nearly 10km!

When six-time London Marathon winner Tanni Grey-Thompson heard about Gwen's fundraising efforts she sent a personal letter of support.

She wrote: "Well done. It is very important to find something that you enjoy doing, it makes it a lot easier to keep going."

The whole school, including Gwen's helper, Non Roberts, supported Gwen by collecting sponsorship and cheering her on as she sped around the track.

Gwen came up with the idea of raising money for ASBAH herself: "I had seen Tanni Grey-Thompson on television and I want to be like her.

"It was difficult because there is a slope by the school gate but I was determined to do it all in one go, and I did."

On yer bike!

The Megacycle is now a firm fixture on the ASBAH fundraising calendar. This year taking place on the 5 – 6th July.

Anyone aged over 18 can take part in the fun event and enjoy the safe and varied eight mile circuit which runs through the beautiful Ferry Meadows Country Park.

Entrants can complete one lap of the course or really put in the pedal power and see how many laps they can total in the 24 hours, either as an individual or as a team.

The event, now in its fifteenth year, has raised more than £35,000 to date and organiser Ian Morley expects this year's event to be bigger and better than ever.

He said: "Every year the Megacycle event gets more popular. There's always a fantastic mix of people taking part some even bring small tents and stay overnight which results in a great atmosphere."

To enter this year's event or find out more about the Peterborough Megacycle, contact Ian Morley on: 01733 421328 (daytime) or 01733 310885 (evening) or by email *ianm@asbah.org*

Alternatively, if you don't want to take part in the actual event but still want to donate visit www.asbah.org

It was my first time at the show and it really was an amazing weekend.

Colin Roberts, ASBAH Director of Fundraising

ASBAH swoops up £12,500

Pigeon fanciers from around the country flocked to the British Homing World Show in January, and helped raise a magnificent £12,500 for ASBAH.

The 36th annual event, held at Blackpool's Winter Gardens, welcomed more than 20,000 visitors who were all eager to view the pigeons and see the trophy presentations for the year's races.

The show is run by the Royal Pigeon Racing Association (RPRA) who first began supporting ASBAH back in 1973. Over the past 35 years, RPRA has donated more than £470,000 from the profits of their renowned annual event.

A team from ASBAH, which included Colin Roberts, Ian Morley and his wife Val, Cerys Long, Sue Knickle and Chris Wheatley, were there to run a tombola throughout the weekend which raised a further £700.

ASBAH's Director of Fundraising, Colin Roberts, accepted the donation from Mr Brian Mead, Chairman of the Show Committee.

Colin told *Link*: "It was my first time at the show and it really was an amazing weekend. I was absolutely delighted to pick up the cheque on behalf of ASBAH and am already looking forward to next year."

ASBAH can now benefit from travel insurance policies taken out by Link readers with Freedom Insurance (be sure to mention ASBAH when requesting a policy). Learn more about travel insurance on page 20.

Don't ditch your phone or ink cartridge... they could raise money for ASBAH

ASBAH has teamed up with a major mobile phone and ink-jet printer cartridge recycling company to raise additional funds.

This initiative will bring in around £5 per recycled phone and 50p per printer cartridge, with the best phones raising as much as £10 each.

The branded ASBAH Appeal envelopes are printed and already available – you'll find one inserted in this issue of Link.

It couldn't be simpler – just place the unwanted phone or used cartridge in the Freepost envelope and pop it in the post (no stamps needed) and the recycling company will recycle the phone and make a donation to ASBAH.

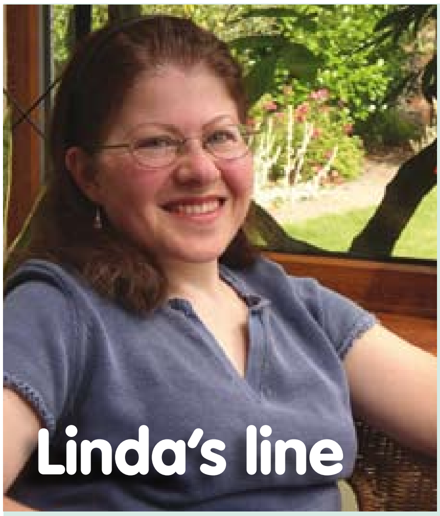
Additional envelopes, in any quantity, are available from ASBAH's Fundraising Department at Peterborough.

We are also placing larger recycling boxes with donor companies and ASBAH will benefit from these collections in the same way.

There are thousands of new mobiles bought every month, meaning that there are an equal number of unwanted ones just waiting to be recycled to the benefit of both the environment and charities like ASBAH.

To make the most of this for ASBAH, please tell family, friends, neighbours and colleagues of this appeal so their old mobiles and cartridges can help our cause.

To request an envelope please email cerysl@asbah.org or call our helpline on 0845 450 7755.



Linda's line

The other day I had a wardrobe malfunction. Not the usual one where I put the wrong colour tights on because I was half asleep when I got dressed, but a more serious one involving my best skirt and a key sticking out of my desk at work, which yanked off around 3 inches of the hem. It turned out to be quite a happy accident in the end, but at the time I was very annoyed.

My colleagues were rather surprised at my reaction, and that wasn't solely due to the rude words that were unintentionally rather audible! The general sympathetic response was "never mind, it's a good excuse to buy another one" and to be honest, I couldn't be bothered to explain why that would be enormously difficult. The problem is that if you happen to be four foot three inches high, buying clothes is often very tricky and if you do not fit a standard size, then whatever you buy is likely to be either too long, too tight, too baggy or impossible to get on. Annoyingly, many of the petite ranges for women under five foot seem to require you to look like the human equivalent of a stick insect (and in case you're wondering, I don't, due to an inability to give up scoffing chocolate).

Equally annoying is the plethora of clothes programmes on the telly, each with their own self-styled guru eager to help a bewildered member of the public solve a clothing "challenge". I use the word loosely, as in many cases they are not exactly much of a challenge – I am thinking particularly of those programmes where the expert comes along to help sort out someone's wardrobe because the owner of said wardrobe thinks her bottom looks big in pink. On a scale of difficulty, that ranks somewhere below feeble.

So, Trinny and Susannah, Gok thingummy and everyone else - if you would like to exercise your professional skills in a challenging and worthwhile project, come clothes shopping with me and find out how difficult it is to buy anything if you are disabled, whether it be pink or otherwise.

I am actually very fortunate, as I can call on the services of a personal shopper in the form of my best friend Sandria. She is brilliant at choosing the right things and whereas I despair after going round two rails of clothes (which are usually too high to see properly anyway) she will happily march round the whole store hunting out bargains. Once we have gathered up an armful of items to try on, she assertively waves aside the stupid "6 items or less" rule and commandeers a changing room with plenty of space and somewhere to sit down. All I have to do is sort out which clothes fit and which don't, and then she does the rest.

Perhaps, by now, you are wondering what was so happy about this accident? Well, my skirt was repaired (at the company's expense) by someone who happened to have contacts with a professional shoemaker. Eager to investigate this further, I have been to visit their workshop in East London and they have agreed to make a pair of shoes for me at a very sensible price, so watch this space!

Age Old Tradition Raises Money for ASBAH

ASBAH was delighted when organisers of a Burns Night party donated all the proceeds to the charity.

Caroline and Judy Savage, Clive Matthews and Catherine Little organised the celebrations which raised £2,200 for ASBAH through donations, ticket sales and a raffle.

Caroline was delighted with the turnout. She said: "We had 160 people there which made the evening really special.

"We were absolutely thrilled with the way the night went. One of the best memories of the evening was my aunt, Lucy, who has spina bifida, dancing in her wheelchair with her Japanese husband, Makoto, who was having the time of his life."

The night began with a champagne reception, the Haggis was piped in and the 'Ode to a Haggis' was recited.

More than 200 years after his death, the life and works of poet, Robert Burns, is remembered every year on 25th January.

Judy Savage commented, "It is so important to involve the next generation in these traditions otherwise they may just fade away."

The evening was organised with the help of many friends including Clive Matthews and Catherine Little who provided the venue, Maiden's Barn, a beautiful Essex barn. Clive and Catherine also organised caterers, a band and a piper to play traditional Scottish music.

Normal Pressure Hydrocephalus

SUPPLEMENT

Contents

Welcome to the latest supplement in our special series.

This time we look at many of the issues surrounding Normal Pressure Hydrocephalus (NPH) from causes and symptoms through to treatment.

We also talk to to *Link* readers who have NPH about how it affects their daily lives.

Of course, if there are any questions you may have which haven't been answered here, you can call the ASBAH Helpline on 0845 450 7755 Monday – Friday, 10am – 4pm (local call rate).

Normal Pressure Hydrocephalus (NPH)

Hydrocephalus is often perceived as a condition affecting babies and children. Normal pressure hydrocephalus (NPH) usually (but not always) occurs in the sixth and seventh decade of life.

What is NPH?

Normal pressure hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) in the ventricles (cavities) of the brain with little or no increase in pressure.

Under normal conditions, about a pint of CSF is produced daily in the adult brain. This circulates through the ventricles and the brain and spinal cord carrying nutrients to the brain and acting as a buffer to prevent injury.

NPH results when the flow of CSF is blocked in some way.

The term "normal pressure" is misleading.

What causes NPH?

In most people, the cause is unknown: in others it can be secondary to head injury or subarachnoid haemorrhage or infection such as meningitis.

It is not hereditary – it does not run in families.

Brain shrinkage is a normal part of the ageing process. The shrinkage causes the ventricles within the brain to enlarge or to appear larger; for normal function, the size of the ventricles must be in proportion to the amount of brain shrinkage.

What are the symptoms?

There are three symptoms common to most people diagnosed with NPH. These are often referred to as a "triad" of symptoms.

These are: gait disturbance
urinary incontinence
dementia

KEY POINT

- **NPH is an abnormal accumulation of cerebrospinal fluid in the ventricles of the brain**
- **Symptoms include walking disturbance, urinary incontinence and dementia**

1. **Gait (walking) disturbance**

   Although there is no "classical" pattern, some people develop a wide based walk whilst others take small shuffling steps; sometimes the expression "magnet gait" is used as people feel that their feet are stuck to the floor and hesitate to take the first step.

   They may have poor balance and have frequent falls.

   Difficulty walking is usually the first symptom that people notice and may lead to a misdiagnosis of Parkinson's disease.

2. **Urinary incontinence**

   This usually starts as frequency and/or urgency. But, incontinence may be due to walking difficulties (unable to reach the toilet in time) or normal consequence of age i.e. prostate problems.

3. **Dementia**

   Dementia is usually mild, progressing to moderate and will include short term memory loss, forgetfulness and difficulty in dealing with everyday tasks. It can be confused with Alzheimer's disease.

Because these symptoms are of gradual onset and are commonly associated with increasing age, many people think that this is the norm and assume that they must learn to live with their problems.

Even GPs and other medical professionals may not initially consider a diagnosis of NPH when presented with a patient with this triad of symptoms.

How is NPH diagnosed?

The initial point of contact is likely to be the GP who should consider referral to a neurologist or neuro-surgeon. The neurosurgeon will watch how his patient walks and may arrange a physiotherapy gait assessment; he will also note how long it takes to answer questions and whether the answers are relevant; he will ask about any urinary problems.

Computerised tomography (CT) or magnetic resonance imaging (MRI) of the brain will show dilated (enlarged) ventricles in NPH and the clinical assessment will include lumbar puncture which will show normal or near normal pressure. This, in some centres, will be followed by infusion studies to check the pressures within the brain.

Can NPH be treated?

At lumbar puncture some 30ml of CSF will be withdrawn. Those patients whose symptoms improve after lumbar puncture are those likely to benefit from surgery. At operation, a shunt (fine tube) is inserted into one of the ventricles in the brain so as to drain the excess CSF and re-route it to another part of the body (usually the abdomen). The shunt is under the skin and is permanent: by this method NPH can be controlled.

Ideally this should be a programmable [adjustable] shunt set at the pressure that is suitable for the person at the time of operation but which, in the future, can be adjusted painlessly in clinic if necessary.

How successful is the shunt operation?

Advances in shunt technology mean that today's treatment will, in the majority of cases, mean an improvement in symptoms.

Will I know if the shunt is not working properly?

Onset of headaches may mean that the shunt is over-draining. This can be minimised by the surgeon using an adjustable shunt so that the doctor can alter the pressure without further surgery. People with NPH may need frequent adjustments in the early months.

If the shunt is under-draining, the walking problems will usually be the first symptoms to re-occur. The neurosurgeon needs to be informed as this may mean that the shunt has malfunctioned.

Further information

For further information on Normal Pressure Hydrocephalus please contact our Helpline on 0845 4507755 to speak to a Specialist medical adviser.

There are two further leaflets on NPH available from ASBAH: one is for people with NPH, the other for relatives of people with NPH. Both are available from the Helpline.

helpline 0845 450 7755

Request for Hydrocephalus Shunt Alert Card and GP Leaflet

hydrocephalus action

TO BE USED IN AN EMERGENCY

I have Hydrocephalus which is controlled by a programmable shunt

association for spina bifida hydrocephalus ability beyond disability

Shunt alert cards

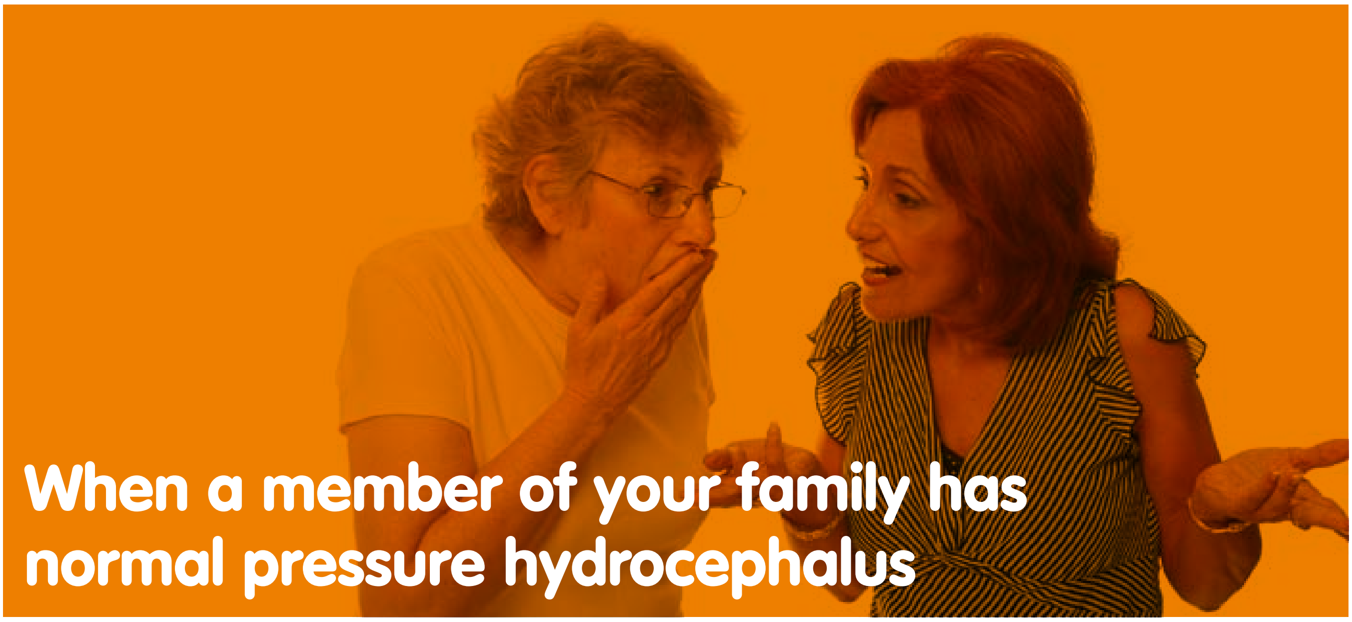
Many adults have registered for one of ASBAH's Shunt Alert Cards . These should be carried at all times by people with hydrocephalus treated by a shunt (this will include some people with spina bifida).

The card emphasises that if the card-holder is showing signs similar to those which occur when there is shunt blockage or infection, urgent assessment of shunt function should be carried out in a specialist neuro-surgical unit, in order to eliminate shunt failure as a cause.

People applying for a Shunt Alert Card can also request that an information sheet about hydrocephalus, specially written for doctors, is sent to their GP.

Employers can ask for "Shunt malfunctions: a guide to symptoms and suggested actions for employers".

The cards are available, free of charge, from ASBAH. Simply call the Helpline on 0845 450 7755 to get yours.



When a member of your family has normal pressure hydrocephalus

Finding out that a relative (or close friend) has been diagnosed with normal pressure hydrocephalus (NPH) can be very worrying.

You will be feeling relieved that someone has made a diagnosis and is talking about the possibility of treatment, but, at the same time, the thought of the tests that your relative will have to undergo, followed by brain surgery, can be scary.

And how is it that your relative has hydrocephalus? Isn't this something that children get? No wonder that this can be a confusing time.

This article will hopefully answer some of your questions and help you to understand what this condition is and how it may affect you as a family.

Your relative or friend will probably, but not always, be aged 60 plus and will probably have had a "triad" of symptoms which are likely to include dementia (forgetting things, sometimes getting confused), mobility problems (he/she may fall a lot, may be unsteady or may have difficulty in picking his/her feet up when walking) and urinary incontinence (sometimes wetting, sometimes having to rush to the loo, sometimes going to the loo over and over again).

If he/she is found suitable for shunt surgery (see ASBAH leaflet Normal Pressure Hydrocephalus for information on tests and shunting), he/she will find that the dementia is less (but some forgetfulness or memory problems may remain); the mobility and the incontinence should be vastly improved – hopefully as good as before the symptoms started.

KEY POINT

- Diagnosis of NPH and treatments
- Frequently asked questions that worried relatives may have, answered by our team of medical advisers

Questions often asked include:

Q) Will NPH shorten my relative's life expectancy?

A) No, once NPH is treated, he/she should expect to live as long as he/she would have done without NPH.

Q) Will he/she be cured?

A) The shunt will treat the NPH but not cure it. Look on it in much the same way as you would a pacemaker or artificial hip – an aid to help things work properly again.

Q) What if the shunt fails?

A) In NPH, the symptoms usually return, often slowly and usually with the walking problems starting first. It is never a life-threatening situation.

Most people with NPH will be treated with a programmable (adjustable) shunt and return of symptoms means that the neurosurgeon needs to adjust it. This is done in clinic, takes about 2 minutes and is totally painless.

People with a fixed pressure shunt (and this is unusual in NPH) may need the shunt replacing.

Q) Will we be able to have a normal life again?

A) Yes, once your relative has recovered from the surgery and has seen the neurosurgeon, you can return to doing everything you did together. At first your relative may tire easily but should gradually get back to normal activities.

Having a shunt poses very few restrictions in older adults whose lifestyle is gentler than when younger.

However, if life includes sports (i.e. skiing, cycling, walking), the ability to enjoy these again should return.

Just be patient – both of you!

Finally, many people wonder who they should tell that their relative has hydrocephalus.

The answer is simple: the people who need to know are those professionals who are involved with your relative like the optician, dentist, practice nurse etc. You would also need to tell the DVLC if they have a shunt fitted and insurers when taking out travel insurance.

After that, it's up to you and your relative. People who know he/she has been ill will obviously wonder what's been wrong and will be pleased they have improved.

Caring for someone who has NPH is frustrating and isolating, as retired GP Alison Edwards can testify.

Living with NPH: a carer's view

Alison's husband Michael, 76, was originally diagnosed with hydrocephalus, due to Arnold Chiari malformation, ten years ago, when his symptoms were primarily difficulty in walking and balance. In the past two years his condition has deteriorated and he now shows the three classic symptoms of NPH: poor balance and co-ordination; memory loss and bladder instability.

Alison said. "When Michael was initially diagnosed as having hydrocephalus he underwent pressure tests. The results were normal so they said nothing else could be done and no follow up was suggested. "But Michael's condition gradually declined until this last year when he got much worse, especially his memory and bladder problems.

In recent years the couple, from Derbyshire, were enjoying their retirement; socialising locally and travelling abroad.

"Now if we try and go anywhere we spend a lot of time looking for toilets. It's such a struggle that it's easier not to go anywhere at all," Alison explained."

"It has been a very difficult year. Until recently we had little support so I could just about get out to take the dog for a walk, but Michael was anxious if left alone for long.

"It took a while but I managed to get help from the local Crossroads charity. Now someone comes in for a four-hour session each week to be with Michael so I can get out. A neighbour also sits with him one evening a week, which is a great help to me.

"I also managed to find a social services respite centre where Michael stayed for a week, enabling me to visit my daughter and grandchildren. The short break was wonderful and just knowing that I have something to look forward to means I can deal with daily life, however tough.

"Accepting that you have become a carer is very difficult, particularly when you're looking after the person you've been married to for 41 years. But it is essential to look after yourself and push hard to get some support.

"I have had spells when I've been very tired and weepy and didn't feel that I was coping at all. It's particularly hard when you have a poor night's sleep.

"It can be difficult to remain calm and patient too, particularly when memory loss means that you hear the same conversation over and over again.

"Most mornings Michael describes his symptoms to me because to him it seems that he's finding them for the first time. I do get impatient sometimes – then of course I feel guilty because he can't help it."

Alison added that caring for someone with NPH is even harder because you are dealing with physical disabilities as well as dementia. "It is so isolating," she said, "as very few people are experiencing the same problems."

It can be difficult to remain calm and patient too, particularly when memory loss means that you hear the same conversation over and over again.

As *Link* was going to print Alison was due to take Michael to see a neurosurgeon at a different hospital in the hope that he could have a shunt fitted to help his condition.

"It has taken a long time to get this far, "she explained. "It seems that the medical profession is often apathetic regarding chronic conditions in the elderly.

"But I'm keeping my fingers crossed that our new neurosurgeon will be able to help and our lives will return to something more like normal."

So you have NPH

You have been diagnosed with normal pressure hydrocephalus (NPH) and, at last, should have a clearer idea of why you have been unwell.

You are probably aged 60 plus (though sometimes younger people get NPH) and have been experiencing a typical "triad" of symptoms affecting your memory, your mobility and your continence.

- Dementia is a general term covering memory loss, confusion, forgetfulness and losing the ability to function as well as you once did.
- Your walking will probably have been affected – you may fall, be unsteady on your feet, be generally slow (even doddery) and have difficulty moving your feet. This may mean that you have to use a wheelchair or are anxious about leaving the safety of your own home.
- And you may have urinary problems which can range from wetting to having to get to the loo as soon as you get the urge. You may have developed "odd" continence difficulties where you feel that you have to go to the toilet very frequently (sometimes every half hour!) and get upset if you can't. This is possibly due to a real fear of wetting and subconsciously you feel that if you keep emptying your bladder, you will cut out any risk of leaking.

All or some of these symptoms may have been present for years. You may have been told that you have Parkinson's disease or early Alzheimer's: both are easily confused with NPH.

However, now you have had a diagnosis from a neurosurgeon who has done tests (or is going to) to see if you are suitable for treating surgically. Or you may already have had the shunt surgery *(See ASBAH information sheet Normal Pressure Hydrocephalus)*.

Whatever position you are in, there are bound to be questions you want to ask and this article will try to answer the most frequently asked.

Q) Am I too old for shunt surgery?

A) No, there is no upper age limit. If the tests show that having a shunt will help you, the neurosurgeon will assess your general physical health when deciding whether you will be fit enough for brain surgery.

Q) Is NPH hereditary? Should I warn my children?

A) No, there is no evidence that NPH runs in families.

Q) What if my shunt doesn't work properly?

A) You will probably have a programmable (adjustable] shunt. If it isn't working properly, you will usually notice your symptoms returning. This will happen slowly and is not life threatening.

Your neurosurgeon may decide to change the setting of the shunt (this is not uncommon); it will be done in clinic, takes a couple of minutes and is totally painless. You will start to feel better after a few days.

Q) Can I drive if I have a shunt?

A) Not for 6 months after the surgery and then at the discretion of your neurosurgeon. He may advise you to go for an assessment.

You should inform the DVLC that you are having a shunt as soon as you get a definite date for surgery.

Q) Can I go on holiday? What precautions should I take?

A) You can go on holiday both in UK and abroad: it is safe to fly, to use Euro tunnel and to go on ferries.

It is advisable not to go through the magnetic security gates at airports etc if you have a programmable shunt, although the newer shunts are highly unlikely to be affected.

As a simple rule, don't go anywhere that people with pacemakers (also sensitive to magnets) are told to avoid.

Before you go, get a letter from your neurosurgeon or GP explaining about your NPH and treatment; you may be able to get a copy of your scan too. Take these in case you have any illness on holiday that means you need to see a doctor.

Ensure that you are properly covered on your holiday insurance – you must declare that you have a shunt. If this causes difficulties, ring ASBAH Helpline on 0845 450 7755 for advice.

Q) What services can I expect when I get home from hospital?

A) This will depend on how you are. You will have been assessed by a physiotherapist whilst in hospital who may prescribe more physio sessions either at the hospital or via your GP.

Hopefully, you will need no more therapy etc than before you were ill.

Q) How soon will I be back to normal?

A) This differs from person to person. You

continued on next page

KEY POINT

- What it's like to care for someone with NPH
- Frequently asked questions about NPH

continued from previous page

should feel better by a couple of weeks after surgery. But remember, this is major surgery you have had or will be having and you're no spring chicken! Just take it one day at a time and you will probably be surprised at how quickly you recover. And don't rush things.

Q) Can I play golf or other sports?

A) Yes, you should be able to get back to doing those things you did before you had NPH and the surgery. Exercise is essential to keep you well and whether it's something active like skiing or golf, or gentler pursuits like walking or swimming, you should aim to get back to it as soon as you feel fit enough.

Q) Can I dye or perm my hair?

A) This is a really common worry - and unfounded! Wait until the surgical wound on your scalp is healed (check with your doctor that it is completely healed over), then go for it! Dye or perm solution will not get into the shunt, which is a completely sealed system.

Q) Can I wear my hearing aid on the same side as my shunt?

A) Yes, they won't affect one another.

Q) Can I still play with my grandchildren? Can they damage my shunt?

A) It is quite safe to play rough and tumble but do avoid being grabbed round the neck. Anything else goes though – you can even join them on their trampoline or bike rides!

Q) Who needs to know about my shunt?

A) People like your doctor, dentist and optician. The first aider at work or the gym or the golf club, your employer and – most importantly –your family.

Ask your neurosurgeon to show you a shunt and get some idea of how it works; having that knowledge and explaining all about it to others will make it much more matter of fact and far less scary.

These are some of the commonly asked questions. Please phone ASBAH Helpline on 0845 4507755 and ask to speak to a Medical Adviser if there is anything you need to know about that hasn't been covered.

Don't worry that your anxieties may be too trivial to bother anyone with: that's what ASBAH is here for!

Ernest Hayfield

Ernest Hayfield, 80, from Sutton-in-Ashfield in Nottinghamshire began to show symptoms of normal pressure hydrocephalus three years ago.

Doctors first believed that he had suffered a stroke and it was 18 months before NPH was finally diagnosed and Ernest was fitted with a shunt.

His wife Doreen talked to *Link* about how NPH has affected their lives.

"I think one of the early signs I noticed was that Ernest began to drive very close to the gutter, but of course he wasn't happy if I commented on it.

"One Sunday morning he dropped me off at Church and set off to return home. But on the way back he actually hit the side of the pavement and when he stopped the car to check on the damage he collapsed, and had to wait for someone to help him up.

A few weeks later one of his golfing friends said that Ernest had stumbled a few times.

Ernest did see his GP and said that he felt under par, but nothing much came from the visit.

Then Ernest fell again, this time in the garden, and wasn't able to get up on his own.

Then I noticed a tremor in his hands. His handwriting was beginning to change too. His flamboyant style was becoming much smaller.

We returned to the GP who thought he might have Parkinson's disease and we were referred to a specialist.

Ernest was quite lucid at the appointment but when he sat on the edge of the bed in the consulting room, he kept toppling backwards.

The specialist thought Ernest had suffered a stroke, and a brain scan suggested that he had bilateral damage.

Back at home his balance became worse and his memory began to fail. Then Ernest became very incontinent and I had to change him several times a day.

My daughter began to do a little research on the internet and she came across some information about NPH.

It was incredible. Every symptom she read about described Ernest's condition exactly. At last we felt there was some light at the end of the tunnel.

We returned to the stroke specialist and mentioned NPH to him. He said it was certainly worth investigating.

Ernest did a memory test – just simple questions such as his date of birth and the name of the Prime Minister. He couldn't really answer any of the questions correctly.

Then he was asked to walk unaided along a corridor, which he couldn't manage at all.

The specialist then did a spinal tap to drain off some fluid. An hour and a half later Ernest passed both the tests with flying colours. It was amazing to see the change in him.

In February 2007 Ernest was finally fitted with a shunt and the improvements were wonderful.

His incontinence problems vanished immediately and although he is still very weak on his legs, he can wash and dress himself and make a pot of tea.

His faculties are improving all the time and he eats and sleeps well too. He's happy to open letters and he wants to deal with them too.

Ernest's consultant saw him in early March and was very pleased with his progress.

It has been a very difficult time for me because there isn't much help available, although our GP and the occupational therapist have been wonderful.

But slowly things are getting easier and I am a strong person. At the end of the day Ernest is my husband and I will care for him as long as my health holds out."

Lack of support can lead to relationship problems

Parents of children with disabilities are more likely to experience relationship breakdowns when they don't receive the support they need, a recent report has revealed.

The study, conducted by One Plus One charity, concluded that the support services they receive are often disjointed and inconsistent, resulting in even more stress.

More than 500,000 children in England have a mild to seriously disabling condition or chronic illness.

The charity discovered that more than half of parents caring for a child with a disability believed that this had caused difficulties in their relationship or resulted in breakdown.

But despite relationship difficulties these parents may be more likely to stay with their partners, which can lead to their children showing evidence of poorer physical and psychological health and behavioural problems.

Families which include a disabled child experience a wide range of pressures, including a lack of support, financial pressures and social isolation.

The cost of bringing up a disabled child is also much higher and often only one parent can work due to a lack of suitable childcare.

These difficulties all contribute to putting huge pressures on a couple's relationship.

The report concluded: "Every family needs one key worker to manage the numerous professionals and agencies that families with a disabled child have contact with.

"That worker should have the skills and confidence to pick up on and work with relationship issues."

The charity's research also showed that the families who do receive enough support and respite care experience less stress from their caring responsibilities and enjoy a better personal relationship.

Penny Mansfield, Director of One Plus One, told *Link*: "Adjusting to the demands of parenthood is a testing time for all couples.

"When their child has a disability, parents face increased financial worries, isolation, stress and the prospect that as their child grows, these problems will not diminish.

"Support for these families to reduce pressure on them must include relationship support. Strengthening the parental relationship of a child with a disability can be a potent protective factor in their life."

"There is no doubt that having a child with additional needs changes family dynamics. Apart from the emotional stress and worry about the welfare of the child, suddenly any number of professionals may be visiting the household, and parents may feel their lives have been taken over with endless appointments at different hospitals, clinics and child development centres.

Not all employers are understanding and it is often very difficult for fathers to take time off work to attend all these appointments without losing pay, so mothers then attend alone with the child, and may have difficulty explaining everything that was said at the appointment. This, over time, can lead to fathers feeling marginalised and mothers feeling overwhelmed and unsupported.

Spending weeks in hospital with my daughter with hydrocephalus with shunt problems, while my husband was at work and also trying to look after our other two children, meant we were not able to give each other the support we needed. Being unable to work and contribute financially, because I was caring for her, meant that we were living under so much stress that it was not surprising that my first marriage broke down."

Valerie

Do you agree with the report findings? Write to the Editor at the usual *Link* address or email *gillw@asbah.org* Please indicate whether or not you would like your name withheld.

New guide gives relationship tips

A new guide has been published for parents of disabled children and professionals working with them, to help strengthen couple and family relationships.

The guide, 'Relationships and Caring for a Disabled Child', is a joint project between the Contact a Family and One Plus One charities, who are concerned about the breakdown of parental relationships.

Jill Harrison, Contact a Family's External Affairs Director, said: "More than half of parents report some, or major, problems in their relationship after having a disabled child.

"This guide provides information and ideas about looking after relationships and will be useful for social workers, counsellors and other professionals working with disabled children and their families."

The guide has been produced using the evidence of 2,000 parents of disabled children surveyed by Contact a Family and research from One Plus One, a charity dedicated to strengthening couple and family relationships.

The guide is downloadable from the Contact a Family website at ***www.cafamily.org.uk/relationships***

Survey results

In a recent Contact a Family survey parents stated the major reasons for relationship problems were:

Stress	**76%**
Tiredness	**72%**
Financial difficulties	**51%**

Many tied these reasons to the additional pressures that come with caring for a disabled child.

Of those surveyed, 78 % of parents caring for a child with profound and multiple learning disabilities currently receive no support or less than two hours per week.

Are you covered for travel?

At this time of year ASBAH's helpline takes many calls from families and individuals planning their summer holidays who are concerned about getting affordable but comprehensive travel insurance.

The helpline cannot recommend particular insurers but does have a list of companies offering policies that will cover pre-existing conditions such as hydrocephalus and spina bifida.

To make sure you get a policy which will provide the cover you need there are a few factors to bear in mind.

It is worth all family members (and travelling companions) appearing on and participating in the same insurance policy.

Although it might seem tempting to try to minimise insurance costs by taking advantage of any "free" insurance supplied, for example, by your credit card provider, or insurance which is included with a package holiday, you need to be aware of possible limitations of these offers.

The problem is that these policies will not usually cover another person's medical condition. For example, a family books a holiday for two weeks in Spain and takes the insurance policy offered by the holiday company.

Because the policy does not cover hydrocephalus the father, who has the condition, takes out a separate policy from rest of the family. A week before the holiday dad has a problem with his shunt and has to cancel. His policy pays the cancellation costs, but only for him.

The underwriters of the policy covering the rest of the family take the view that they are not covering someone else's medical condition and will not respond to the claim.

The same would apply to a curtailment of the holiday, the need for repatriation, or if a member of the party is required to stay on beyond the due return date to receive continuing medical treatment.

If you are taking out annual travel insurance make sure that any medical conditions declared when the policy is taken out remain the basis of the contract throughout the year so that any deterioration in the declared condition and any new conditions that emerge after the start of the policy will be covered.

It is very important to remember that it is up to you to declare anything that may affect the offer of insurance cover – for example, a company may not ask if you have hydrocephalus but you need to tell them if you do.

It is worth asking questions to make sure the policy you are taking out will meet your particular needs such as:

- Cover for mobility and disability equipment including standard and electric wheelchairs;
- Special cover for carers;
- Cover for lost, stolen or damaged medication.

Then with the right cover for you, you can look forward to your holiday knowing that if there is a problem the help you need will be provided.

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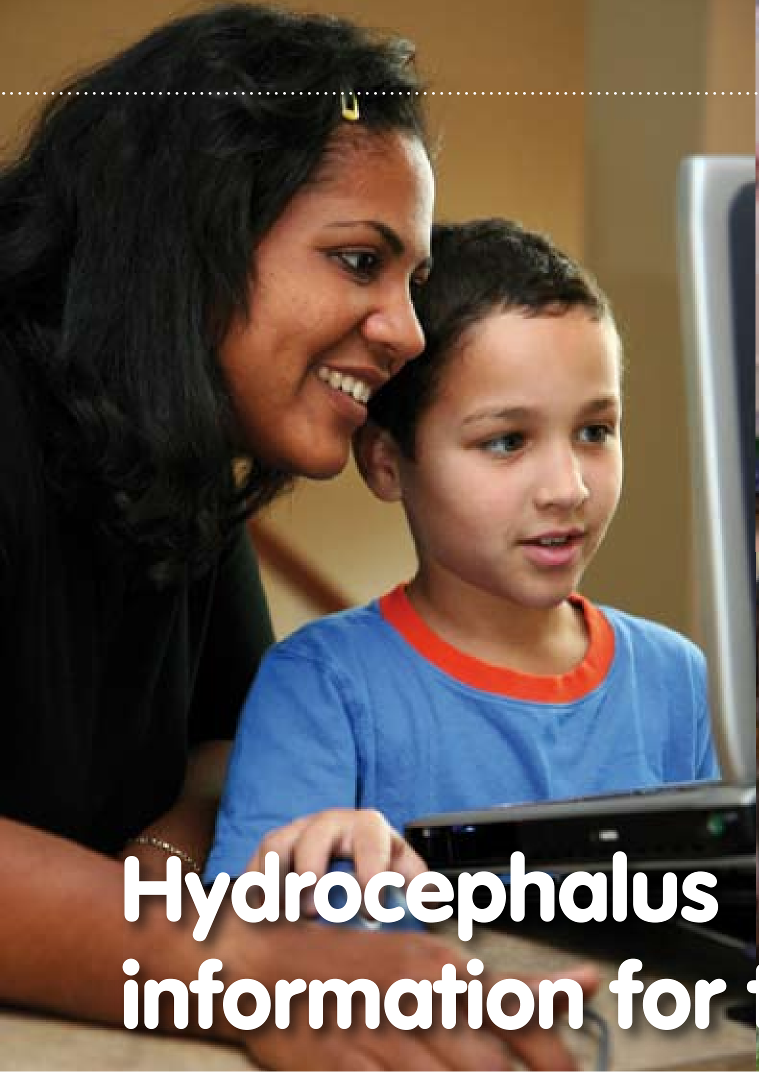


Hydrocephalus information for teachers

ASBAH has launched a new education booklet to make teachers aware how hydrocephalus can affect a child's learning.

'Hydrocephalus and its implications for teaching and learning' was published in February thanks to a Children in Need grant.

The eight-page booklet was written by ASBAH's education adviser Carol Rubinstein in consultation with ASBAH's Education Advisory and Medical Advisory Committees.

It includes an introduction to hydrocephalus and how it affects the brain and learning.

There are detailed sections about issues and learning strategies to help children with hydrocephalus improve their memory, organisation and concentration.

Visual perception, language and comprehension, Maths and social and behavioural skills are also covered in full.

The booklet concludes with health and safety information concerning shunts, plus a recommended further reading list.

Carol told *Link*: "I have received many enquiries from teachers and parents about general progress.

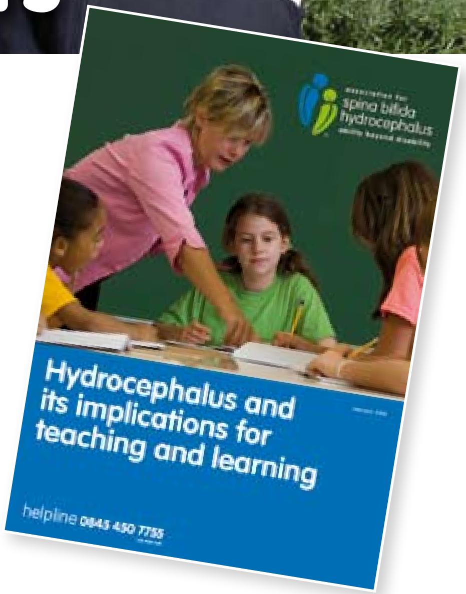
"A lack of understanding of hydrocephalus often leads to inappropriate targets being set and unhelpful teaching strategies being employed.

"When teachers understand particularly the memory and language difficulties, many of them are prepared to adapt their delivery of information to take account of the different learning styles and intelligences of the children which, in turn, can lead to much improved progress."

A lack of understanding of hydrocephalus often leads to inappropriate targets being set and unhelpful teaching strategies being employed

The booklet is available from ASBAH by calling the Helpline on 0845 450 7755. The cost is £9, which includes postage and packing.

Carol added: "It would be very useful if parents who have a child with hydrocephalus suggest that their school buys it."



association for spina bifida hydrocephalus

Hydrocephalus and its implications for teaching and learning

helpline 0845 450 7755

Carol is hoping to write a similar booklet aimed at parents in the coming months, so watch this space…

In the next Link we will be looking at 'Statementing and your child' and what does going to school really mean for families and carers with a disabled child.

Codman - Working in partnership with ASBAH

> Having the operation was the best thing she could have had...now she has grown and straightened up so much and I know she's much happier about herself.

Chloe Wall

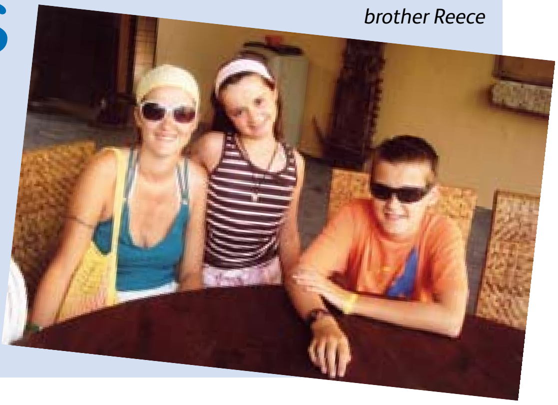
Posterior Fusion Rods

Posterior fusion rods to help correct curvature of the spine have come a long way since they were first developed in 1953 by Dr Paul Harrington from Houston,Texas.

Today spinal screw and rod systems are normally made of titanium (such as the those supplied by DePuy) so the patient can be MRI scanned post operatively.

The surgeon also places a large amount of bone graft material that, once fused into bone, will become the spine's supporting structure. The fusing process takes around 6 to 12 months.

Below - Mum Joanne, Chloe and her brother Reece



Chloe's story

Chloe Wall had spinal rods inserted three years ago when she was eight years old.

The youngster, who has spina bifida, could walk quite freely with the help of splints but was affected by curvature of the spine.

Her mother Joanne was understandably nervous about her daughter undergoing the operation, but looking back she says it was "the best thing we could have done".

> Chloe is a fantastic girl, so lively and chatty, and I'm thrilled that she has so much confidence.

Here Joanne, from Holmwood in Bradford, talks to *Link* about the operation and how it has helped Chloe.

"Chloe's spine has always been curved and she suffered from constant backache.

When she was X-rayed as part of a routine orthopaedic check-up it was noticed that the curvature was becoming much worse. The consultant said he would like to operate and use fusion rods to help straighten Chloe's spine.

I have to admit that I was terrified. The only previous operation Chloe had undergone was when she was born. You read so many stories about operations going wrong that I was very frightened.

But we didn't really have an option. The curvature and resulting pain would have got worse and worse.

After the operation Chloe was kept in hospital for a week. She has a huge scar down her back so it was very difficult to move her to change and clean her.

The day she returned home she had chicken pox, with spots all over her back, which didn't help matters.

Chloe was off school for six weeks but I think it took at least three months before she was running around as normal. I think Chloe was worried that too much movement would open the scar – that wasn't the case, but she obviously felt fragile for a while.

Having the operation was the best thing she could have had. I suppose I was so used to seeing Chloe's curved spine that it just seemed part of her.

But now she has grown and straightened up so much and I know she's much happier about herself.

Her spine isn't completely straight but the improvement is huge. She still has pain in the lower back and around the hips, but we're told that is related to her spina bifida and not the curvature.

Chloe is a fantastic girl, so lively and chatty, and I'm thrilled that she has so much confidence.

She was continually being asked by children at school why she wears splints and why she never uses the toilet.

So in the end she asked the teacher if she could give a talk. She spoke to the whole year group – 60 children – and explained what spina bifida is and the complications.

She even told them why she uses a side room to change rather than using the toilet and took examples of continence products to show.

It all went really well and now she is accepted for who she is. I do feel sorry that she is restricted in the summer clothing she can wear, but on the whole, spina bifida doesn't stop her doing very much at all."

What is ETV?

Endoscopic third ventriculostomy (ETV) is a procedure used to treat hydrocephalus as an alternative to a shunt.

Although the procedure, which is a natural way of draining the CSF fluid from the brain, is only suitable for a small percentage of hydrocephalus patients, it has many advantages over shunting.

The main method of treatment uses shunts to drain the cerebral spinal fluid (CSF) from the ventricles in the brain to another part of the body.

The change in his personality was so dramatic, as was the change in the family atmosphere. At last it seemed that we had our son back.

Brett Wilkie

Brett's story

Brett Wilkie from Surrey has undergone 35 operations during his 28 years – many of which were shunt revisions.

As he got older, constant headaches became a feature of his life and affected Brett's personality and lifestyle, even though surgeons believed his shunt to be working correctly.

During the summer of 2003 the headaches seemed to get much worse. Brett described them as "thumping, mainly on the left side at times to an almost unbearable extent."

As a result he became very angry and moody and found the pain made him question his ability to work.

Research convinced all of us that we should investigate the possibility of this operation for Brett.

At this stage Brett and his father, Jon, began to research spina bifida and hydrocephalus on the internet, and learnt about the ETV procedure, which could alleviate the need for the shunt completely.

Jon told *Link*: "Further research convinced all of us that we should investigate the possibility of this operation for Brett.

"If he was suitable for the operation we thought it could be the solution to his problems."

After discussions with his surgeon, Brett underwent an ETV, his 34th operation, in August 2003.

He was discharged several days later after his consultant announced that the operation seemed to have been a complete success.

According to his father, Jon, the changes to Brett have been nothing short of miraculous.

"The immediate difference to Brett was the fact that the constant headaches disappeared.

"The change in his personality was so dramatic, as was the change in the family atmosphere. At last it seemed that we had our son back.

"Although all the signs were so good, it was difficult to believe that we had reached a point where we could consider a future for Brett which was free from headaches and continued shunt operations."

Jon added: "Today Brett leads a normal life and his personality has returned to the wonderfully happy, good-natured and kind lad we knew a long time ago.

"He now works at the local Tesco super store in Brooklands handling customer complaints and returns on the electrical desk. His speech hesitation has almost disappeared completely.

"We feel very, very lucky, but Brett is the luckiest of all!"

KEY POINT

- Chloe's spinal rods prove a great success
- ETV as an alternative procedure in treating hydrocephalus

YV website – one year on

The Your Voice website is gaining in popularity with new members signing up all the time.

The site, launched in February 2007, now boasts 83 registered users, including 5 overseas members… one lady lives in Mauritius in the Indian Ocean.

"The website has opened up many opportunities for Your Voice," said YV Policy Officer, Barbara Robinson.

"As well as keeping everyone up to date with events, members can respond to current issues in the Have Your Say section, such as the recent consultation on "Improving Specialist Disability Employment Services."

But perhaps one of the biggest advantages of the site is the message board and forum areas where users can post and respond to comments.

Barbara said: "At last people who have spina bifida and/or hydrocephalus can get in touch with others in the same position, to share experiences. I think it particularly helps those who feel isolated.

"Several people have also posted queries which our YV committee members have responded to."

Barbara said that she was thrilled that people from overseas have signed up to be associate members - a special membership category was created to allow them to enjoy the benefits of the website.

"Like all new projects the website has taken a little while to take off, " she added, "but we are finding that more and more people are logging on all the time."

To use the forums…

To join YV Forums you must be a member of Your Voice. This is free and open to those who are aged over 18 years and have spina bifida and/or hydrocephalus.

You can sign up using the online application form or if you need more information please contact Barbara Robinson, YV Policy Officer, at barbarar@asbah.org or call her on 01733 421 322.

www.yourvoicegroup.org

Issue 2 out now

The second issue of the Your Voice newsletter is hot off the press and is packed with news and views from around the group.

The newsletter, which can be downloaded from the website, became an instant hit when it was launched last year.

In this issue an overseas member, Dario, from Italy, writes about his life and interests.

There are articles from ASBAH medical adviser Lisa Raman, who talks about her role in the organisation, while Linda Lewis writes about the work and successes of the Helpline.

With an event review, committee member profile and Paul Mann's piece on the trials and tribulations of train travel, there's plenty to read.

Get your copy from the website or by contacting YV Policy Officer Barbara Robinson on 01733 421322, email *barbarar@asbah.org*

Your Voice presents

Open to all adults (aged 18 and over)

Looking Good Feeling Great

Social, leisure and self image

Date and venue:

Friday 11th July to Sunday 13th July 2008

Worsley Park, Manchester

Book NOW

Weekend delegate rate £95 includes accommodation, workshops and meals.

Day delegate rate £30 (Saturday 12th only) includes workshops and lunch.

The delegate rate is being subsidised by Your Voice

About the next event:

This event is to mark the end of the Comic Relief Funding.

We are intending to have a photographic exhibition promoting Your Voice and to also show what the Your Voice group has achieved during the Comic Relief Funding.

For further information and to register your interest contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 421322

association for
spina bifida
hydrocephalus
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Transition Clinic


Frank Lee

Consultant Urologist Frank Lee has run a successful and highly regarded Transition / Adolescent Clinic at St George's Hospital in south London for the past four years.

The clinic, which operates once a fortnight, is designed for continuing the care of around 120 patients with spina bifida once they have reached their late teens.

Here Frank talks to Link about the clinic and how he hopes it will develop in the future.

1. How are patients referred to the Transition Clinic?

I receive referrals from different sources including my paediatric colleagues locally and from the neighbouring regions, in and outside London, and GP's

2. Is there an overlap with the paediatric clinic?

My paediatric urology colleague, Su-Anna Boddy, and I do a 'handover' clinic once or twice a year, so that patients have the chance to meet me, their new doctor, in a familiar environment, in the presence of their 'normal' doctor and nurse specialists.

3. What makes it different from the paediatric clinic?

As the patients get older, they begin to attend the clinic without their parents sitting in.

We have full discussions with them to ensure they are ready to take on more responsibilities. Usually this is a time when they expect more autonomy and freedom so they need to accept the responsibilities which come with that.

4. Does the clinic empower patients to take charge of their own care?

Yes, this is the idea. We are always here to help but they will have to start taking some responsibilities as well, with more participation in caring for themselves and decision-making.

5. It is looking towards independence from parents' care?

Yes that's absolutely right. It is a 'walking and standing by you approach', rather than carrying you on my back.

6. What is the age range of patients you see?

The majority of my patients are between 16 to late 20's. Of course, there will be a small number of patients in their 30's and 40's.

7. Why will a patient attend your clinic?

They feel they get on well with myself and my team. I think it is the personal style that matters most.

Being a man, I am in a better position to talk more openly with the young men who may have questions about their sexual health.

8. What are the benefits to patients?

They are being looked after in a multi-disciplinary setting with everything they may need provided under one roof. At present, I am working very hard to make it a one-stop, same day process, e.g. same day ultrasound.

9. Is the clinic a cost-effective way of seeing patients?

Yes, I cannot come up with another model at present but I do believe in the Utopia goal of a Consultant-delivered, rather than Consultant-led service.

10. Do other hospitals run similar clinics?

Yes, there is a very good set up at Chelsea and Westminster Hospital, led by Dr Richard Morgan and Mr Nick Madden. I work very closely with them.

11. How successful do you personally rate the clinic?

On a scale of 1 to 10 with, 10 being the best, I would rate it as 7 at present.

It is a very well established clinic but there are several improvements I would like to see made.

The most important change would be to make it a consultant-delivered service. At the moment I try and see every patient and build up a good working relationship with them, but unfortunately I can't see everyone myself on every visit.

12. What are the other changes you would like to make?

I would like to see a sharing of facilities and resources.

St George's Healthcare Trust recently opened a new Atkinson Morley Wing and also runs the Wolfson Rehabilitation Centre in Wimbledon, both of which have excellent facilities.

I believe it would make sense for us all to operate under one umbrella, allowing us to tap into a wider range of resources and access the wider expertise available.

KEY POINT

- A Transition Clinic that helps to encourage young adults to independence and empowerment

Below the Belt advice

ASBAH's new book helps address some of the many issues facing teenagers with spina bifida and/or hydrocephalus.

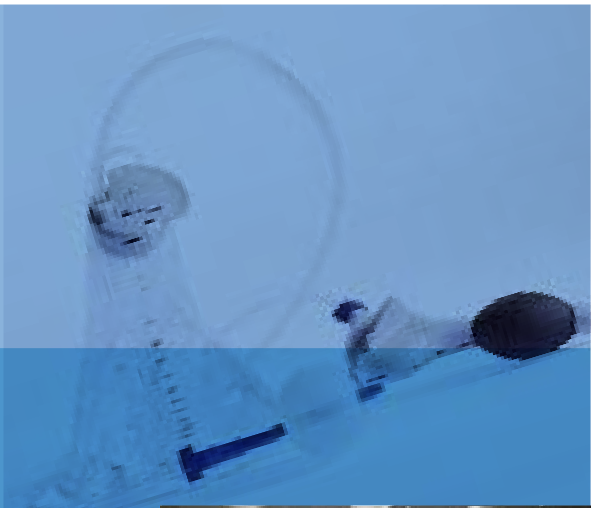
The 32-page Below the Belt book was launched last year and has been praised for its practical advice.

The A4-sized publication is packed with useful information and advice on matters which affect teenagers, from continence issues through to relationships and sex.

Phone ASBAH's helpline on 0845 450 7755 for details of how to obtain your copy.

Coloplast - Working in partnership with ASBAH

Members of ASBAH and the Spinal Injuries Association (SIA) got together for the first time to discuss all aspects of bowel management.



Getting the low down on bowel management

The event at the Holiday Inn, Aylesbury, which was supported by Coloplast, gave service users a comprehensive guide to the importance of good bowel management and the various options available to them.

Paul Smith, chief executive of SIA, opened the meeting with a talk about bowel management options to ensure that everyone received the best possible care.

He was followed by Dr Maureen Coggrave, a research nurse from the National Spinal Injuries Unit at Stoke Mandeville, who presented her research into bowel management for people with a spinal cord injury.

> **It was interesting to hear people's personal experiences of using Peristeen and how it really had changed their lives. Bowel accidents usually become a thing of the past once a routine is established.**

The audience of 35 – which included six *Link* readers - heard first hand how Michael Cogswell, a member of the Great Britain disabled sailing team, can now travel the world with confidence after he was introduced to the Peristeen Anal Irrigation system three years ago.

Rosemary Batchelor, ASBAH's senior medical adviser said: "It was interesting to hear people's personal experiences of using Peristeen and how it really had changed their lives. Bowel accidents usually become a thing of the past once a routine is established.

"One important thing which came out of the session was that Peristeen does not always work like magic. Some people find they get into a routine very quickly but some find it needs a few weeks of perseverance before the person gets used to it and find they have confidence in their new bowel management regime.

"Support from a continence adviser or health care professional is essential for success. Some GPs are prescribing it with no one there to offer support, and that's a recipe for failure."

The afternoon session featured a lively question and answer session with the speakers and ASBAH's Gill Yaz.

"As everyone had been so open about their experiences, the audience was relaxed enough to discuss pretty much anything," Rosemary added.

The meeting ended with Rosemary thanking Coloplast, which supported the event, and all the guest speakers.

What is Peristeen?

Peristeen Anal Irrigation is a way of emptying the lower bowel and is used to prevent faecal incontinence, or constipation, or simply as a method of bowel management.

It has been specially designed to make it portable and easy to use, which gives independence and confidence to the user. It's also time-saving - taking on average 30 minutes to perform every other day.

It can be used by people with a variety of bowel problems, and in clinical trials with Spinal Injured patients, the Peristeen system reduced faecal incontinence and constipation and improved the quality of life.

Peristeen Anal Irrigation is available on prescription but you can get further information by calling Charter Healthcare on 0800 132787. You can request a leaflet and DVD explaining more about the product.

Coloplast is currently arranging dates and venues for further Bowel Management days. For further details please contact Sarah Clark at Coloplast by emailing gbscl@coloplast.com or call 01733 392349.

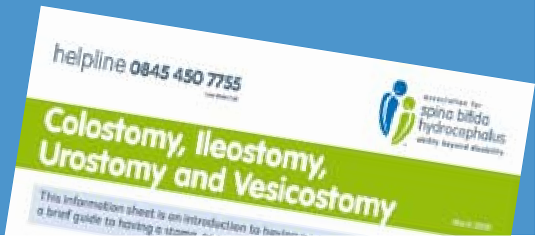
KEY POINT

- A report on the recent Coloplast bowel management event
- We introduce the new continence information leaflets

Coloplast - Working in partnership with ASBAH

ASBAH's medical advisers have been working hard to complete a special project – a comprehensive continence pack.

Get clued up on continence


helpline 0845 450 7755

Colostomy, Ileostomy, Urostomy and Vesicostomy

This information sheet is an introduction to
a brief guide to having a

Although information sheets on continence issues have been available for some time, we felt a thorough revamp was needed to bring them up to date.

It was a huge project which involved collaboration with some of the most experienced nurse specialists and occupational therapists around the country, but the results have proved well worth the effort.

The new pack of information sheets is aimed at both service users and their carers and professionals.

Individuals can request the leaflets specific to their needs while professionals will be able to buy the entire pack for a small £5 charge.

Lisa Raman, ASBAH's national medical adviser who led the project said she is thrilled with the end result.

"It is our belief that the information in this packet will be valuable at every stage of life for many of our service users and also for those who care for them," she said.

As the spina bifida population ages, there will be many people who have never had their continence issues addressed.

New parents are likely to be bewildered at having to face up to their disabled child's continence problems.

But the pack of ten leaflets brings together all the information individuals, carers and parents will need as well as answering many of the questions which are frequently asked.

The topics covered cross the spectrum, beginning with potty training children with spina bifida and/or hydrocephalus, with medical information and plenty of practical tips.

Medical information sheets include an introduction to having an ostomy or stoma, with explanations of terminology, how to prepare for surgery, post operative care and how to look after the stoma.

The Mitrofanoff surgical procedure - to create a stoma (small opening) - is explained in full in another section.

Other leaflets in the substantial pack include detailed explanations of the ACE procedure, artificial urinary sphincter (AUS), Clean Intermittent Catheterization (CIC) and Bladder augmentation

With dietary advice to prevent constipation and details of adaptations for toilets, the medical advisers feel that the subject of continence is well covered.

Lisa added: "ASBAH would particularly like to thank the specialist nurses from around the country, who provided much of the information.

They are all members of the PUCSIG (Paediatric Urology and Continence Special Interest Group). The support from such a knowledgeable and resourceful group of experts is invaluable to us."

Get your copy

Individuals can get individual leaflets specific to their needs by downloading them from the ASBAH website ***www.asbah.org*** or by calling the ASBAH Helpline on 0845 450 7755 (local rate call).

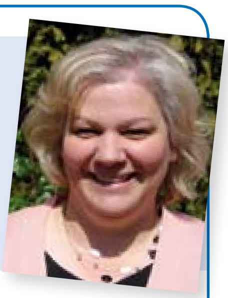
Professionals, such as school nurses or community paediatricians, can buy the complete pack for £5 (inc p&p) by calling the Helpline.

Get Clued up on Continence

The pack contains leaflets on:

- **Toilet Training and Spina Bifida**
- **Toilet Training and Hydrocephalus**
- **Dietary Advice**
- **Adaptations for Toileting**
- **Colostomy, Ileostomy, Urostomy and Vesicostomy**
- **Mitrofanoff Procedure**
- **ACE Procedure**
- **Artificial Urinary Sphincter (AUS)**
- **Clean Intermittent Catheterization (CIC)**
- **Bladder augmentation**

Lisa Raman, ASBAH's national medical adviser



"Although continence is taken for granted as not very exciting or important to many people, it becomes the single defining factor in quality of life and independence for those who struggle to manage their bowels and bladder.

We, along with our sponsor, Coloplast, understand the need to present relevant information about modern bowel and bladder care for the ASBAH community.

So ASBAH medical advisers tapped the knowledge of the most experienced nurse specialists and occupational therapists around the country to revise our high quality continence leaflets, aimed at making continence easier to understand and manage in the least invasive way.

The result of the collaboration is a revised comprehensive packet of vital information; ranging from basic topics like dietary advice and toilet adaptations, to highly complex surgical procedures that specifically address the needs of our service users.

It is our belief that the information in this packet will be valuable at every stage of life for many of our service users and also for those who care for them."

ASBAH is very grateful to Coloplast for sponsoring the Continence Pack which is part of the campaign to increase awareness of bladder and bowel health.

In legal terms we have the names you can trust

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Anthony Fairweather
Wills, Trusts and Court of Protection
T: 0845 209 1265
anthony.fairweather@clarkewillmott.com

Kerry Fifield
Medical issues
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Diary dates

Contact your regional office for more details on the following dates:

Eastern Region Local Association Forum Meeting

Date: Saturday 5 April 2008
Time: 11.00 am start
At: ASBAH House, 42 Park Road,
Peterborough PE1 2UQ
Lunch and parking
Speaker: Colin Roberts, Fundraising Director
More information contact the
Eastern Region Office on: 01733 421309

Eastern Region Looking Ahead with Hydrocephalus

Date: Wednesday 14 May 2008
At: East Midlands Conference Centre
University Park, Nottingham
Aimed at 12 to 25 years of age
More information contact the
Eastern Region Office on: 01733 421309

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

A group for adults with spina bifida and/or hydrocephalus and their carers meets every two months at Roydon Village Hall, High Road, Roydon, Nr Diss, Norfolk. Parents of teenagers with spina bifida and /or hydrocephalus are also very welcome.

For further details please contact Margaret & Alan Twyford on 01728 860916 or by email to ***twyfords@aandmtwyford.plus.com***

The following dates have been fixed so far:
8 May 2008 6.30-9.30 pm
July 2008
September 2008

ASBAH AGM 2008

Location: Leicester
Date: Wednesday 24 September 2008
A new venue and a new style. For more details please contact Lyn Rylance at ASBAH by calling 01733 421356 or email ***lynr@asbah.org***

Northern Region Dates for York Drop-in 2008

Low Moor Community Centre, Bray Road,
Fulford, York YO 10 4JG
2nd Wednesday each Month - 10.15-12noon
9 April • 14 May
11 June • 9 July • 13 August
For further information please contact the Northern Region Office on 0113 255 6767 or email ***sylvieb@asbah.org***

2008 Summer Experience

11-14 August
For further information please contact the Northern Region Office on 0113 255 6767 or email ***nro@asbah.org***

Your Voice presents: Looking Good Feeling Great

Theme : Social, Leisure and Self Image
Location: Worsley Park, Manchester
Date: Fri 11 July 2008 to Sun 13 July
For more details see page 24.

Have Wheels Will Travel

Location: Leicester Marriott
Date: Friday 31 October 2008 to
Sunday 2 November

Contact Barbara Robinson on ***barbarar@asbah.org*** or call 01733 421322 to book or reserve your place in this and any future Your Voice event.

Please e-mail the editor (Link@asbah.org) dates of your events for the next issue of Link by Friday 16 May 2008, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Letters

We welcome letters for publication, which should be sent to: Editor, Link, 42 Park Road, Peterborough, PE1 2UQ. The editor reserves the right to edit letters, so please keep them short.

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New staff for N&W Yorkshire ASBAH

Exciting times are ahead for the North and West Yorkshire local association which recently boosted its staff team.

The group secured funding for two new members of staff, both on two-year contracts.

Elizabeth Davenport, who has joined as full-time Activities Facilitator, is already working hard on her first task to find volunteers to help with activity groups throughout the area.

Charlotte Wilson has been employed as a part-time administrator. Her role is to get the website up and running as well as maintaining the database, taking caravan bookings and writing for the association's Newslink newsletter. Email Charlotte on ***nandwyasbah@aol.com***

Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of *Link* should be submitted by Friday 16th May 2008

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This issue we meet Linda Corbett who has penned our popular Linda's Line column for the past five years.

Linda Corbett

Transferring funds of more than £3 million or speaking to the Falkland Islands' Chief of Police about someone missing at sea… it's all in a day's work for Linda Corbett.

While she may be better known to Link readers for her dry wit and devotion to guinea pigs, Linda revealed that her day job, four days a week, is Pensions Manager for the Merchant Navy Officers Pension Fund.

"Working a four-day week is the best arrangement I've ever negotiated," she laughed. "Having Fridays off to catch up makes a huge difference."

> **Whilst discrimination was a huge problem for me, things have certainly got better, although I think there are still issues for many people.**

Linda certainly needs extra time to juggle her many commitments which include voluntary work at a church near her Cheam home and her new role as Fundraiser for Surrey ASBAH.

Then of course there are the articles she writes for *Link* and developing her family history website.

By 7.30am each working day Linda is at her desk, reading through new legislation papers or writing reports to the Pension Fund trustees.

She said: "I am an early bird by nature and getting to work early helps because I escape the worst of the traffic on the M25.

"I also find it easier to concentrate on the more detailed work when the office is peaceful.

"My alarm goes off at 5.45am and I rush around like a lunatic, grabbing some breakfast, feeding the guinea pigs and getting ready.

"Unfortunately the early starts do backfire. I've been known to put on the oddest colour combinations because I'm rushing to get out on time.

"Only the other week I stood up to leave a meeting and realised that I'd put on an olive green skirt and navy tights. It looked awful and I was mortified!"

Linda joined her company two years ago, and it's a role she clearly relishes.

"No two days are the same," she explained. "I am dealing with paying benefits to real people who have been at sea for much of their lives. Pensions is my work not my hobby, but it is a very interesting career."

But when she first began job hunting after 'A' Levels, Linda despaired of ever finding a career.

She said: "I have a long history of problems with my feet and that did affect my job prospects because there have been several periods where I was in and out of hospital.

"It also didn't help that people with disabilities were discriminated against in the 1980s.

"On several occasions I would be accepted for an interview, but the employer would take one look at me and show me the door even though I had two Maths 'A' Levels, plus Economics.

"To begin with I just didn't know what to do. Once I went home, locked myself in my room and cried my eyes out.

"But I did learn to be clever and become economical with the truth to override any obstacles. I also realised that if I was to be taken seriously I needed to study for professional qualifications.

"I needed to prove that it was my brain which mattered, not how long my legs were.

"Whilst discrimination was a huge problem

KEY POINT

- **Linda Corbett tells *Link* about her busy life**
- **How Linda has overcome discrimination**
- **Her love of guinea pigs**

for me, things have certainly got better, although I think there are still issues for many people.

"I am fortunate in that I now have 24 plus years experience to fall back on and a piece of paper that says I am a Fellow of the Chartered Insurance Institute and an Associate of the Pensions Management Institute.

"That certainly opens doors in a way that my early attempts at employment negotiation did not!"

When Linda was putting her energies into pulling herself on to the first rung of the career ladder, romance was the last thing she expected.

It appeared in the form of Andrew, a former colleague, who was clearly captivated at first sight.

Not so for Linda. "I have to admit that I didn't like him much to begin with," she laughed. "But things began to look up at my works leaving do."

Just fourteen weeks later the couple were engaged and married a year later in 1990.

As regular readers of Linda's column will know, there's never a dull moment in the Corbett household, particularly with a blossoming family of guinea pigs - Harriet, Milly, Roger and Biscuit - who clearly rule the roost.

Linda said: "I've always adored guinea pigs and it is lovely having a tribe of them because they have lovely temperaments. They really give a lot back even if they have run up enormous vets bills in recent years!"

Contacting ASBAH

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