

Pack Guide

This pack has been written and designed to provide information and signposting for the families and carers of people diagnosed with an Acquired Brain Injury (ABI). The pack contains information about ABI and outlines the support available from Headway West Sussex (HWS) as well as other organisations that may be of use to you.

We have divided the pack into sections to make it easier to follow and access as you need to.

INFORMATION

This section contains information that will help you understand the possible effects of ABI. It also has information about Headway West Sussex Services.

- Factsheets from Headway UK.
- Headway West Sussex Support Groups with all relevant contact information.
- Information about our Counselling Service
- Information about our Support & Information Service

BENEFITS

Following an ABI you may be entitled to benefits which could be in the form of tax credits, disability or carers allowance. Here we have provided the information that will help you find the organisations to assist you should you need further help.

LEGAL ISSUES

It may be that you or your family member has suffered an accident where there are issues of compensation, liability or other claims to be dealt with. Whilst HWS cannot offer you legal advice, in this section, we have provided information that will signpost you to the most appropriate sources of information and advice.

CARERS INFORMATION

HWS recognise that being a carer can often be difficult and comes in many forms, so in this section you will find information about the role of a carer, details about organisations that can offer support, signposting and information. We try to make sure the details are relevant to your local area, but a call to the organisations contact number should direct you appropriately.

- We have included a free copy of the Headway UK Booklet "Caring for Someone with a Brain Injury" by Richard Morris in the pack.



Headway West Sussex is affiliated to Headway UK The Brain Injury Association
Helpline: 0808 800 2244

Headway West Sussex www.headwaywestsussex.org.uk

SIGNPOSTING

We are aware that everyone's needs are different and there may be other services that you require. For that reason, in this section, we have provided a cross-section of contact details for organisations both local and nationwide which you may find useful.

ADDITIONAL RESOURCES

Further reading and publications

Also in the pack:

- Wallet card with contact details for the Headway UK nurse-led, freephone helpline.
- Smart Card should you ever get into difficulties.
- We may have included some additional information that is pertinent to your situation.

A diary/notebook for your own use to:

- Keep a daily record of your progress to take to clinic.
- Write down any questions you want to ask your clinician.
- Write down their answers as well (if you are not able to do this, or have a memory problem, consider taking someone with you)
- Inside will find NHS guidance on questions to ask when seeing a healthcare professional.

Each year 4500 people in West Sussex suffer an ABI



“Coming to Headway has improved my life 100%”



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Introduction

HEADWAY WEST SUSSEX

Who we are

HWS was formed over twenty years ago by the families of two survivors of Acquired Brain Injury (ABI). HWS is affiliated to the national charity Headway UK but remains a charity in its own right.

What is an ABI?

Acquired Brain Injury (ABI) is defined as non-degenerative injury to the brain occurring since birth. It can be caused by an external physical force or by metabolic derangement. The term 'acquired brain injury' traumatic brain injuries, such as open or closed head injuries, or non-traumatic brain injuries, such as those caused by strokes and other vascular accidents, tumours, infectious diseases, hypoxia, metabolic disorders (e.g. liver and kidney diseases or diabetic coma), and toxic products taken into the body through inhalation or ingestion.

What are the effects of an ABI?

There are obvious visible severe effects such as paralysis, loss of speech, coma etc. But then there are the less obvious, the ones that are not visible and they may include:-

Loss of identity	Memory Loss	Problems with Concentration
Inability to make Decisions		Disorganisation
Depression	Anger	Extreme Fatigue
Mood Swings	Fear (of it happening again)	Loss of identity

After ABI

ABI, when it happens, can be a devastating event for all concerned, for both the person who has suffered the injury and their family. Brain Injuries come in many forms and levels of severity, but however low or severe the damage, the effects can be deeply felt. This is why HWS also offers support to families and carers.

“HWS means support for me and my husband. Carers have needs too.” - Carer HWS Support Group

In this section we have included fact sheets on:

1. The effects of brain injury.
2. Caring for someone with a brain injury - The early stages after injury.
3. Others that may be useful to you.

These and many factsheets are downloadable from the Headway UK website. If you do not have access to a computer please contact your Support Group Facilitator or the Headway West Sussex office and we will be pleased to help you. All the topics are covered more fully in booklet form and they are available to buy from Headway UK.

www.headway.org.uk/shop.aspx
Telephone 0808800 2244



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Introduction

OUR AIM

Improving lives after Acquired Brain Injury

What we do

- Provide information about brain injury and the issues around it
- Run Support Groups for people with an ABI and carers.
- A Counselling Service.
- A free Family & Carer information pack.
- Support & Information service.

How you can help us

If you would like to support us as a volunteer or by fundraising please get in touch with our office.

Headway West Sussex contact details

Website: www.headwaywestsussex.org.uk

Email: info@headwaywestsussex.org.uk

Office: **07938 858153** Our office is open on a part time basis

Support & Information Service: **074671 88500**

Headway Freephone nurse led helpline: **0808 800 2244**

Open Mon – Fri 9am - 5pm

Twitter: [@HeadwayWS](https://twitter.com/HeadwayWS) Facebook:
www.facebook.com/headway.westsussex

Headway West Sussex regrets that it is unable to

- Give Clinical advice – Please contact your GP or call the Headway UK helpline which is nurse led.
- Recommend practitioners/residential care facilities/rehabilitation services/solicitors (Headway UK have an approved provider list, available on their website and in this pack in the legal section).
- Provide transport to the support group meetings.
- Please see our website for further group criteria.

Headway West Sussex is a charity in its own right and must raise all its own funding. Without your support we cannot provide the services in West Sussex that are so urgently needed. You can support us by:

Text **HWWS00 £10** or any amount you can give to **70070** to donate to Headway West Sussex & make lives change.

You can go to our [Virgin Giving page](#) and make a one off donation, a regular donation.



You can also raise fund for us by running, swimming, jogging, walking, cycling, abseiling or anyway you fancy! Set up your own JustGiving page or get in touch with us for help. Without you and your support we cannot do this:

“Headway also arranged for me to get to the support group meetings in Horsham and I learnt so much more about head injuries from others there that had ABI too. Headway West Sussex do a fantastic job. I now understand my condition and have come to terms with it. I might not be able to do what I used to, but I am now living a ‘different’ life but it is an ‘independent’ life again which is more than I ever thought I could.”

-Brain Injury Survivor



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Support Groups

SUPPORT GROUP INFORMATION

The support groups are free and open to people with a clinically diagnosed ABI their families, carers and friends.

The groups focus on topics that can affect people living with brain injury, such as fatigue, memory problems and anxiety. The facilitator guides a group discussion and information is available to take home and new members will receive a family and carers information pack. The facilitator will talk to you about other services we offer and can signpost you into them. We sometimes have guest speakers who are experts in their field of ABI and from other West Sussex based charities. There is also time for refreshments, chatting and socialising. You can attend as much or as little as you like and those who attend the groups are welcome at our Social Groups.

Please contact the Support Group Facilitator before you attend the group to find out more and confirm time and venue.

WORTHING SUPPORT GROUP & BOGNOR REGIS SUPPORT GROUP

Support Group facilitator – Helen Canning 07531 146516
worthingsupportgroup@headwaywestsussex.org.uk

CRAWLEY SUPPORT GROUP & HORSHAM SUPPORT GROUP

Support Group facilitator – Graham Manvell 07747574077
crawleysupportgroup@headwaywestsussex.org.uk

"It helps having the support of others who understand ABI – I don't feel alone anymore."

- Support group member

"I had not left my flat for three years, then I came to a support group. Later that week I went out to play cards with my old friends."

- Support group member



Benefits

THE NEED FOR BENEFITS

Claiming

When someone in the family has had an ABI you may be entitled to claim State benefits for yourself as a carer or for the person with the AB. This can be a challenging situation and it is important that you get the right advice and claim the appropriate benefits for your situation.

DWP Benefit Enquiry Line

Benefit Enquiry Line:
Freephone 0800 882 200
Text phone 0800 243 355

Opening Hours Monday to Friday 8.30am to 6.30pm

Email: BEL-Customer-Services@dwp.gsi.gov.uk

You can also visit the Direct Gov page learn more about these benefits.
www.direct.gov.uk/disability-money



The Advice line telephone number is 0344 477 1171
Available Monday to Friday 9am - 5pm.

In this section you will find:

1. A Headway UK Welfare Benefits Checklist.
2. Factsheet with guidance on completing the claim form.

Other useful numbers The Headway Emergency Fund

To help families and individuals cope with the practical implications of a sudden catastrophic brain injury.
Tel: 0808 800 2244

Independent Living Fund

Support for disabled people enabling them to choose to live in the community.

Tel: 0845 601 8815

www.ilf.org.uk

fax: 0115 945 0945

Email: client.service@ilf.org.uk

Turn2Us

Helps people access benefits, grants and other help. website: www.turn2us.org.uk

HWS is not responsible for the contents of other organisations websites. All information is correct at the time of printing.



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Legal Issues

HWS cannot give you legal advice, however, on the right side of this page is a list of Headway UK Approved Providers for Sussex, they have expert knowledge and experience of handling claims for people with ABI.

A UK wide version is available from the HWUK website or phone 0808 800 2244 for a copy.

MEETING YOUR SOLICITOR



Before you meet your solicitor it is a good idea to get together any letters, documents or other paperwork which you think the solicitor might need to see. For instance, if you have been involved in a car accident the police may have given

you a card or a letter with some details on about the accident e.g. time, place, reference number (if in doubt show the solicitor the document and they will decide if they need the document or not).

It is also advisable to take any insurance policies that you may have to the meeting so that the solicitor can check to see if you have any legal expenses insurance.

Questions To Ask Your Solicitor

A solicitor who is prepared to act for you or your family should not object to answering questions fully and honestly.

For a full list of questions to ask your solicitor see the Headway UK website:

www.headway.org.uk/Questions-to-ask-your-solicitor.aspx

Claiming Compensation Booklet

For more information on making a claim and the issues involved, you may like to consult the Headway publications 'Claiming Compensation after Head Injury', written by a leading personal injury solicitor this helpful booklet explains the litigation process in a straightforward way and is available from Headway UK for £3.50.



All of the providers listed are part of the HWUK Approved Provider scheme and have specialist knowledge and training in the field of ABI. They can also give you advice regarding Power of Attorney and The Mental Capacity Act, or if you are seeking compensation.

UCKFIELD

Rix & Kay Solicitors LLP
1 The Drive
Brighton & Hove, East Sussex
BN3 3JS
Tel: 01732 440855
alexbrown@rixandkay.co.uk

CHICHESTER

George Ide LLP
79 St Pancras, Chichester
PO19 4NL
Tel: 01243 786668
Claire.watson@georgeide.co.uk

CRAWLEY

ASB – Aspire LLP
Innovis House, 108 High Street
Crawley
RH10 1AS
Tel: 01293 603603
Francis.lacyscott@asb-aspire.com

BRIGHTON

ASB – Aspire LLP
44-46 Old Steine, Brighton
BN1 1NH
Tel: 08450 636465
Francis.lacyscott@asb-aspire.com

Mayo Wynne Baxter LLP
Century House
15-19 Dyke Road, Brighton
BN1 3FE
Tel: 01273 775533
jlingwood@mayowynnebaxter.co.uk

Carers

Caring can take many forms and to be regarded as a carer you do not have to be carrying out personal physical care for someone. If you are collecting prescriptions, doing the shopping, helping with the housework or any other type of task that assists another person to get on with their life then you are a carer. The role of a carer should never be underestimated and it can be a complex area.

Below are details of services dedicated to offering support to carers whatever their caring responsibilities.

Carers Support

To find your local services or for free confidential information and advice call **0300 0288888**.

Lines are open 9.00am-8.00pm Monday to Friday (except bank holidays) 11am to 4pm at weekends. Calls are free from UK landlines and mobiles or you can request a free call back.

www.carers.org/carers-services/find-your-local-service

Crossroads Care Emergency respite care

01403 243924

Email admin@crossroadscare-sc.org

www.crossroadscare-sc.org

Crossroads Care General information South Central

01903 790270

Email admin@crossroadscare-sc.org

Contact a Family

020 7608 8700

www.cafamily.org.uk

Helpline/ Text phone **0808 808 3555** (10am-4pm, Mon-Fri)

The Princess Royal Trust for Carers/Young Carers

Unit 14, Bourne Court, Southend Road, Woodford Green, Essex
1G8 8HD

0844 800 4361

info@carers.org

www.carers.org

Watch our Headway West Sussex carers film - [CLICK HERE](#).



We have included a FREE copy of the HWUK booklet 'Caring for someone with a Brain Injury' in this pack.



Signposting

In this section you will find a selection of leaflets and a list of useful telephone numbers and organisations. If you haven't already been allocated a social worker, then you will find a list of all the local area contact numbers for Adult Social Services. Where possible we have given a local telephone number but the contact centre should provide you with local information.

<p>HEADWAY UK</p> <p>The charity that works to improve life after brain injury. Provides information, support and services to people affected by brain injury, their family and carers.</p> <p>www.headway.org.uk</p> <p>Email: enquiries@headway.org.uk</p> <p>Tel. 0808 8002244</p>	<p>UK CARE HOMES</p> <p>Find a suitable Care Home and supported living accommodation.</p> <p>www.carehome.co.uk</p>
<p>SAMARITANS</p> <p>Confidential support for anyone in crisis –</p> <p>www.samaritans.org</p> <p>Tel 0845 90 90 90.</p> <p>Local number will be on the website or in the telephone directory</p>	<p>CITIZENS ADVICE BUREAU</p> <p>The Citizens Advice service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers. To find the number of your local office call 08444 111 444</p>
<p>IMPACT – INITIATIVES</p> <p>Advocacy</p> <p>advocacy@impact-initiatives.org.uk</p> <p>Tel. 01903 730044</p> <p>Support with returning to work</p> <p>workability@impact-initiatives.org.uk</p> <p>Enquiries</p> <p>www.impact-initiatives.org.uk</p> <p>email: info@impact-initiatives.org.uk</p>	<p>P.A.L.S. (Patient Advice and Liaison Services)</p> <p>Crawley, Horsham, Mid. Sussex and surrounding areas 01293 600300 ext 3965</p> <p>ws-pct.nwscapals@nhs.net</p> <p>Rest of Sussex 01903 505456 – same email for general contacts.</p> <p>FOR COMPLAINTS 01903 708557/708057 spctc.complaintswestsussex@nhs.net</p>
<p>S.A.B.I.F. (Sussex Acquired Brain Injury Forum)</p> <p>Service Directory</p> <p>www.sabif.org</p> <p>DisabledGo</p> <p>Provider of access information for disabled people in the UK, featuring over 120,000 places of interest. Every single venue featured has been visited in person by a specialist surveyor.</p> <p>www.disabledgo.com</p> <p>Email: enquiries@disabledgo.com</p> <p>Tel: 0845 2704627</p>	<p>Headway UK Approved Provider Scheme</p> <p>Find an approved provider who has meet Headway UK standards.</p> <p>www.headway.org.uk/approved-provider-scheme.aspx</p> <p>Tel: 0808 800 2244</p>



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Signposting

<p>THE CHILDRENS TRUST</p> <p>National charity, which runs the UKs largest rehabilitation centre for children and young people with ABI. They also provide community based support to children and families around the country and run the Brain Injury Hub: www.braininjuryhub.co.uk - a website offering information, practical advice and a discussion forum to parents and other family member.</p> <p>The Childrens Trust, Tadworth Court, Tadworth, Surrey. KT20 5RU</p> <p>Tel. 01737 36500</p> <p>Email: enquiries@thechildrenstrust.org.uk</p>	<p>DIFFERENT STROKES</p> <p>Charity for young stroke survivors aiming to provide access to exercise, physio, information and counselling.</p> <p>Helpline 0845 130 7172</p> <p>www.differentstrokes.co.uk</p> <p>Email: info@differentstrokes.co.uk</p>
<p>BEHIND THE GREY</p> <p>www.behindthegrey.net - an online support community for those whose lives have been affected by a subarachnoid haemorrhage or stroke.</p>	<p>NHS MEDICAL RECORDS</p> <p>You may want to access your medical records – for information on how to go about this go to www.nhsmedicalrecords.org.uk</p>
<p>BRAIN TUMOUR UK</p> <p>Brain Tumour UK is working towards a world free of the fear of brain tumours. Delivering breakthrough support, information and research on the path to the cure.</p> <p>0845 4500 386</p> <p>www.braintumour.org.uk</p> <p>Email: enquiries@braintumour.org.uk</p>	<p>BRAIN AND SPINE FOUNDATION</p> <p>Research, education and information, On-line discussion forum. Helpline staffed by neuroscience nurses.</p> <p>Tel: 0207793 5900</p> <p>Fax: 020 7793 5939</p> <p>Helpline: 0808 808 1000</p> <p>www.brainandspine.org.uk</p>
<p>B.I.R.T. The Brain Injury Rehabilitation Trust</p> <p>60, Queen Street, Normanton, Wakefield. WF6 2BU</p> <p>Tel: 01924 896 100</p> <p>www.birt.co.uk</p>	<p>Trust Ed</p> <p>Provide educational services for young people with acquired brain injuries</p> <p>www.trust-ed.org</p>
<p>Brain Tree Training</p> <p>Produce home-based cognitive rehabilitation courses for those with acquired neurological injuries.</p> <p>Tel: 01276472 369</p> <p>www.braintreetraining.co.uk</p> <p>Email: enquiries@braintreetraining.co.uk</p>	<p>Connect</p> <p>Connect is a charity for people living with aphasia, a communication disability which usually occurs after stroke.</p> <p>For general enquiries (Head office):</p> <p>Tel: 020 7367 0840</p> <p>Email: info@ukconnect.org</p>

All details are correct at the time of printing; you can inform us of any changes using the contact details in the Introduction section of this pack - Thank you.



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Signposting

Requesting Social Care Support

You may be allocated a social worker at the hospital, if not you can request support via the contact details below:

Email: socialcare@westsussex.gov.uk Please include the area in which you live and a phone number if the matter is urgent.

Or you can write, visit or phone through the offices listed below.

You may also prefer someone - such as a friend or your GP - to make contact for you.

Please note that all calls to any of the office phone numbers below are first handled by the Contact Centre.

<p>BOGNOR REGIS Durban House Durban Road Bognor Regis PO22 9RE Phone: 01243 642400 Fax: 01243 642437</p>	<p>CHICHESTER 1a East Row Chichester PO19 1PD Phone: 01243 752999 Fax: 01243 752644</p>	<p>CRAWLEY 3rd Floor Crawley Library Southgate Avenue Crawley RH10 6HG Phone: 01293 895100 Fax: 01293 895114</p>
<p>HORSHAM County Hall North Chart Way Horsham RH12 1XH Phone: 01243 642555 Fax: 01403 213125</p>	<p>SHOREHAM Glebelands Middle Road Shoreham BN43 6GA Phone: 01273 268800 Fax: 01273 268801</p>	<p>WORTHING Centenary House Durrington Lane Worthing BN13 2QB Phone: 01903 839100 Fax: 01903 839248</p>

Emergencies

Helpline for social care emergencies out of office hours.

Phone: **01903 694422** weekdays between 5.00pm and 8.00am.

The helpline covers weekends and bank holidays 24 hours a day.



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Resources

Further Reading

The first list of books are publications that Headway UK recommends and are available from their website.

Head Injury a Practical Guide - Powell	£18.00
Head Injury - The Facts Daisley, Tarns & Kischka	£12.00
Coping with Memory Problems - Clare & Wilson	£13.50
Living with an Acquired Brain Injury Workbook - Hedley	£25.00
My Parent has a Brain Injury - Johnson	£9.99
My Mum makes the best cakes - Johnson	£4.99
My dad makes the best boats - Johnson	£4.99

Other Publications

This list is of books that our members have recommended, we hope you find them useful. However, Headway West Sussex does not accept responsibility for their content.

Touching Distance - James Cracknell & Beverley Turner
Fractured Minds - Jennie A. Ogden (paperback)
Never Ending Journey: Living with Brain Injury - Antionette Anthony Pillai
Cracked - Recovering after Traumatic Brain Injury - Linsey Calderwood
Dipped into Oblivion - Sacha Bonsor
On the Edge - Richard Hammond
Time Out of Mind - Jane Lapotaire
Over my Head - Claudia L. Osborne
Where is the Mango Princess? - C.E. Crimmins
Falling and Laughing - the Restoration of Edwin Collins - Grace Maxwell

Some of these books are available to Support Group members to borrow from us.

Please contact your Support Group Facilitator who can advise you.

