

LINK Activities



New LINK Website Launch

Brighton and Hove LINK is pleased to announce the launch of its new website. It features informative new content, along with enhanced navigation and usability. It has been fully tested by LINK participants including those with disabilities.

The main aims of our new website are to:

- °encourage sign-up to the LINK
- °promote members of the public to give their issues on health and social care
- °provide information on the LINK and its work

“Our new website reflects the LINK’s key messages and will enable the public to access all the information they need easily. We’ve tried to make it as interesting and fun as possible; there’s an interactive virtual Brighton to submit issues.” Claire Stevens, LINK website manager.

On the LINK website you’ll be able to:

- ° submit health and social care issues online
- ° quickly and easily sign-up to the LINK
- ° take part in surveys and polls
- ° find out all the dates and more information on LINK meetings and events
- ° access key information on the LINK
- ° access all the LINK’s minutes and reports
- ° watch videos from LINK volunteers and the NHS
- ° find out more about who’s who in the LINK

Websites can always be improved so if you have any comments (good or bad) please contact claire@cvsectorforum.org.uk
www.bhlink.org.uk

What’s inside LINKletter?

- The latest news and information on health and social care.
- Update on LINK activities
- Opportunities to take part in surveys and consultations to improve health and social care
- Competitions

LINK News

LINK Annual Event – Health and Wellbeing

Please make sure you keep Saturday 24 July (11am to 3pm) free in your diary. Our annual event will be a fun, informative day and everyone who lives, work and studies in Brighton and Hove is welcome. We are hoping to attract a wide variety of people, particularly those who don't usually attend health events. The event's theme is health and wellbeing from keeping active, to taking up hobbies and feeling good about yourself. There will be a wide range of activities available from face painting for the kids, nail art, craft, healthy eating demonstrations and blood pressure checks. See the enclosed flyer for more details.

Win £150

Can you create a cover for the Brighton and Hove LINK Annual Report? It's open to everyone who lives, works or studies in Brighton and Hove. More information at www.bhlink.org.uk

This month we've been asking service providers about:

- Chlamydia screening
- Smoking cessation
- Diabetes
- Access to health information and support for people with sensory impairment
- Funding cuts
- Public toilets
- Dentistry

If you have anything to say about these issues, contact us. The more views the LINK receives the more we can do to help!

Here's what you've been telling us in April:

- “I can't find an NHS dentist in my area.”
- “Not enough open loos in Brighton.”
- “I want more support for my diabetes.”
- “They got the wrong name over my hospital bed.”
- “Waited too long at the Walk-in Centre in Brighton.”
- “I didn't want to see men's private parts from my hospital bed.”
- “I don't want to go to bed at 8 o'clock but that's what time my carer comes.”
- “I received excellent care at Knoll House, I was very pleased.”
- “The eye hospital was really good with my young son.”

Got something to say about local health and social care? Tell us!

LINK in the Community

This month Val Young, Development Worker has been spreading the word and work of LINK and gave a talk at the Alzheimer's Society support group for carers currently caring for someone with dementia at home. Some of the issues raised were around hospital discharge, patient transport, where to get information from and delivery of person-centred dementia care in hospitals.

Val also gave a talk at an open public meeting on Health in Whitehawk and Manor Farm. These meetings are designed to give residents the opportunity to discuss health issues and feed into a representative neighbourhood forum. Main items under discussion were the new Wellsbourne Health Centre and the pharmacy.

LINK News

Complaints

LINK Steering Group Member Geraldine Des Moulins and LINK Manager Claire Stevens met with the Complaints Team at Brighton Sussex University Hospitals NHS Trust (BSUH). The Trust provides acute care in Brighton and Hove including Royal Sussex County Hospital, Royal Alexandra Children's Hospital and the Sussex Eye Hospital.

The LINK wanted to find out more about how the Trust handles complaints following some concerns from members of the public who contacted the LINK. If you have recent experience making a complaint to BSUH please contact the LINK.

We asked the Trust to provide more information on how to make a complaint for our newsletter, you can see this article on page 6.

Hospital Discharge

We are looking for the views of anyone who has been discharged from hospital in Brighton and Hove in 2009 and 2010.

- Did you feel that you received enough information?
- Did you feel ready to be discharged? Happy to look after yourself at home?
- Were you offered support and contact details of people who can help you after discharge?
- Did you find the experience good or bad?

Please contact us with your views or join the LINK Hospital Discharge Group.

LINK Annual Report

The LINK has a legal obligation to produce an annual report which is submitted to the Secretary of State for Health.

This report will be approved at the LINK Steering Group meeting on the 23rd June.

This is a meeting in public so everyone is welcome.

Copies of the final report will be available from our office and on our website in July.

Good News, LINK Success

The LINK heard from local residents that wheelchair users could not access Hove Park café.

The LINK contacted a local Hove councillor, expressing their concern. The good

news is that BHCC is working with the café now to ensure there is disability access so everyone can enjoy this beautiful park and its facilities.



Opportunities with Brighton and Hove LINK

Media Spokesperson Vacancies

Have you got experience working with the media? Could you help the LINK respond to enquiries from journalists, draft press releases? You will need to be able to respond quickly to requests and be willing to undergo training.



The LINK can be contacted by phone, post or email.

By post:
Freepost RSGY-UXAC-ZZZG
Brighton and Hove Local Involvement
Network
BRIGHTON
BN1 4GQ

Telephone: 01273 810235
Email: info@bhlink.org.uk
Website: www.bhlink.org.uk

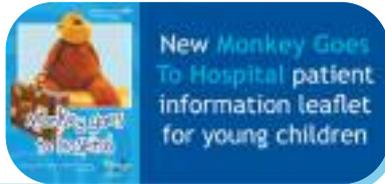
Local News

New Hospital Leaflet for Children

Helen Sadler, a mother from Brighton, came up with the idea for a new book *Monkey Goes to Hospital* after her daughter Josephine became a regular visitor to the Royal Alexandra Children's Hospital. Josephine, aged two, recovered well from pioneering key hole surgery for a serious lung problem last year.

Free copies of 'Monkey goes to hospital' are now being given out at the Royal Alexandra Children's Hospital to help prepare and reassure both children and their parents.

You can download a copy of this book from www.bsuh.nhs.uk



Have your say on the new Brighton and Hove Hospital

If you are signed-up to the LINK you are invited to the Teaching, Trauma and Tertiary care (3Ts) (new hospital development) team meeting on the 17 June. You will work with them to help design the 'flagship' areas and rooms of the new hospital. This is a great opportunity to help shape the design of the hospital. Thursday 17th June, from 09:00 until 12:30 at the Brighthelm Centre. More details and to book contact

john.wilkinson@bsuh.nhs.uk
Telephone 01273 523415.

Involvement Opportunities

The NIHR Research Design Service South East funded by the National Institute for Health Research (NIHR) helps improve the design of health research in Kent, Surrey and Sussex. They are looking for people to get involved in the design of a health research study.

The role includes:

- ensuring that everything is written clearly and not in medical 'jargon'
- deciding how to recruit people to a research study so that they don't feel under pressure or distressed
- deciding how to weigh up which of two treatments is best
- choosing what questions to ask people.

Any payment or covering of your costs would be decided between you and the researcher and financed by them. To find out more contact Joanna Wunsch 01273 644064 J.Wunsch@brighton.ac.uk

Mental Health Gateway Meeting

If you are Interested in local Mental Health Services, come along to Mind's quarterly Gateway Meeting on 9 June from 12.30 – 3.30pm at South Wing, Community Base, 113 Queens Road, Brighton BN1 3XG.

Everyone is welcome – whether you have experienced mental health issues, or care for someone with mental health issues, or just have an interest in mental health – come along and meet service providers and have your say about how to improve mental health services, in a relaxed and friendly environment.

The focus of this meeting will be on proposals to redesign the Access and Recovery services.

Light refreshments will be available but feel free to bring your own lunch along. For more details contact Julie, Mind's LIVE Project Co-ordinator on 01273 666950.

Free Health Checks

FREE NHS Health Checks in the workplace and community settings, targeting men aged between 40 -74 years (women are also eligible). The aim of the health checks is to help prevent heart disease, stroke, diabetes and kidney disease. The Health Checks are part of national scheme from the Department of Health to help prevent the onset of these health problems. By having the health check and following the advice of the health professional, you improve your chances of living a healthier life.

Tony.Wright@brighton-hove.gov.uk

Appointment of B&H's first learning disability training nurse (Sussex Partnership NHS Foundation Trust, SPT)

To meet the needs of people who have both a learning disability and a mental health need, SPT has appointed its first learning disability training nurse working in Brighton & Hove community mental health services. The new role also involves raising awareness of the needs of people with this dual diagnosis and training on methods of support.

www.sussexpartnership.nhs.uk

National Health & Social Care News

Treatment differences for poorer prostate cancer sufferers

A recent study published in the British Medical Journal of men treated for prostate cancer has found poorer patients were 26% less likely to have radiotherapy and 52% less likely to have radical surgery. Dr Georgios Lyratzopoulos, who led the study said "There are two possible reasons why men from less well off backgrounds do not get the same treatment. Firstly, they have a higher degree of other illnesses, which means having radiotherapy or surgery may put them at greater risk. Also, the way these people process information about the pros and cons of various treatments may be different from those higher up the social ladder."

Dr Sarah Cant, Head of Policy and Campaigns at The Prostate Cancer Charity said "Treatment for prostate cancer will be different for each man and choosing the right treatment can be a complicated decision. It is important that all men receive accurate and comprehensive information and have the opportunity to discuss their treatment options fully with their doctor. If men do not receive the information they need or do not feel able to discuss this with their doctor they may be less likely to be able to participate in decisions about how they should be treated."

All men regardless of their background, should be aware of their right to information about all the treatment options available to them, so that they can work with their doctor to choose the treatment that is right for them.

www.prostate-cancer.org.uk

An end to bottom flashing hospital Gowns

As part of a project to improve dignity across the NHS hospital gowns have been redesigned. The old gowns have been criticised for leaving patients feeling exposed. The new gowns designed by fashion designer Ben de Lisi offers more comfort and does not have the back and bottom exposed. The new designs funded by the Department of Health will be available in early 2011.



Your Chance To Have Your Say in National Consultations

Tissue Donation - Have Your Say

The Nuffield Council on Bioethics is running a consultation on the ethical implications of various ways of trying to increase tissue donation.

With a focus on whether people should be expected to donate organs, eggs and sperm, and asks questions including:

- How far should we as a society go in encouraging or even incentivising people to provide material?
- What control should a person providing material have over its future use?
- Can useful comparisons be made with people taking part in 'healthy volunteer' clinical trials where people 'give over' their body for a short time for research purposes?

Closes 13 July 2010, to find out more and to take part, phone 020 7681 9619 or see www.nuffieldbioethics.org.

New Secretary of State for Health



Andrew Lansley CBE was appointed on the 13th May as Secretary of State for Health. Mr Lansley is the MP for South Cambridgeshire and previously served as the Shadow Health Secretary – a position he held from 2003.

Mr Lansley said: "I am determined that we will have an NHS in which the patient shares in making decisions; where quality standards are evidence-based and form the basis of the design of services and their management; and where the objective is consistent improvement in the outcomes we achieve, so that they are amongst the best in the world. This will not happen in a top-down, bureaucratic system. Decisions must be taken with patients, close to patients and with clinical leadership at the fore."



Monitor: Regulators of NHS Foundation Trusts

Monitor is the name of the independent body that regulates NHS Foundation Trusts.

Its three main roles are:

- Determining whether a trust is ready to become an NHS Foundation Trust
- Ensuring trusts comply with the conditions they signed up to and
- Supporting the development of NHS Foundation Trusts

www.monitor-nhsft.gov.uk
Telephone 020 7340 2400

How to make a complaint – Brighton Sussex University Hospital Trust

If you are unhappy about the care you have received at BSUH NHS Trust please ask to speak to the person in charge of the ward or department concerned if you are currently in the hospital. They may well be able to resolve things straight away.

You can also raise concerns via the Patient Advice and Liaison service (PALS). PALS provides information and on the spot help for patients, their families and carers, working to resolve concerns quickly by liaising between you and the hospital staff. PALS can also provide advice and information should you wish to pursue matters more formally.

If you would like your concerns to be investigated more formally you can contact the complaints department either in writing or by telephone or by the BSUH Trust website www.bsuh.nhs.uk (linked to Complaints, Compliments and Comments section).

If you need independent help to make a complaint you can contact the Independent Complaints Advocacy Service (ICAS). ICAS can help by supporting you through the process and representing your wishes and feelings. They will help you explore the options for taking your complaint forward. ICAS can also provide help with interpreters if there are language difficulties. You can contact ICAS on 0845 600 8616.

We will do everything we can to resolve your concerns with you. This may include a written response and/or arranging a meeting with relevant staff from the hospital. If you are unhappy with any aspect of our response please come back to us in the first instance. It is our intention to resolve things locally if at all possible.

Patient and public engagement tool launched online

A new online tool has been launched to help the NHS unlock the benefits of effective patient and public engagement in health. Called 'Invest in Engagement', the site analyses and makes accessible the results of 280 research reviews. www.pickereurope.org/investinengagement

Patients Unaware Of Fatal Blood Clot Risk (*The Daily Telegraph*)

Half of former surgical patients questioned by a survey for Lifeblood (Thrombosis Charity) said no one discussed the risk of blood clots that develop while in hospital prior to or after their surgery. The survey showed that MRSA, hospital food and noisy wards were greater causes of concern for patients despite blood clots causing an estimated 25,000 hospital deaths each year. www.thrombosis-charity.org.uk Tel: 01558 650222

NICE launches public webpage

The National Institute for Health and Clinical Excellence has launched a new page on their website that will allow, for the first time, patients, carers and members of the public to search for the versions of guidance that are written for them all in one place.

www.nice.org.uk/patientsandpublic/

Health and Wellbeing

Prostate Cancer

June is **male cancer awareness** month so we're focusing on prostate cancer. Prostate cancer develops in the prostate, a gland in the male reproductive system.

Symptoms

The following symptoms may show that you have a problem with your prostate. However, most men with early prostate cancer have no symptoms at all. These symptoms can also be caused by other prostate problems that are nothing to do with prostate cancer.

- A weak or reduced urine flow
- Needing to urinate more often, especially at night
- A feeling that your bladder has not emptied properly
- Difficulty starting to pass urine
- Dribbling urine
- Needing to rush to the toilet – you may occasionally leak urine before you get there.

Less common symptoms include:

- Pain when passing urine
- Pain when ejaculating
- Pain in the testicles
- New pain in the lower back, hips or pelvis
- Problems getting or keeping an erection
- Blood in the urine or semen – but this is rare.

If you have any of these symptoms, you should visit your GP to find out what is causing the problem. Remember some men with prostate cancer may have no symptoms at all.

Diagnosis

Prostate cancer and other prostate problems can cause similar symptoms but are treated differently so it is important to get an accurate diagnosis. However, most men with early prostate cancer have no symptoms at all. In order to find out what is causing your prostate problem, your GP will ask you about any symptoms and may carry out some tests. The results of these tests will tell you and your doctor more about what, if anything, is wrong.

The tests that your GP can do are:

- First, a urine test to rule out infection, and if this is negative, then a blood test to measure the PSA (Prostate Specific Antigen) level in your blood
- A physical examination called a DRE (Digital Rectal Examination)

Hospital tests that you may have are:

- TRUS (Trans-Rectal Ultra Sound) guided biopsy
- CT scan
- MRI scan
- Bone scan with or without X-rays

The TRUS guided biopsy will tell you if prostate cancer has been found, while the rest of the scans are usually done to 'stage' a cancer once it has been found. Some of these tests may not be carried out if the diagnosis is clear without them.

No one knows how to prevent prostate cancer but diet and a healthy lifestyle may be important in protecting against the disease.

Risk Factors

Prostate cancer mainly affects men over the age of 50. Younger men can be affected but this is rare. The risk of developing prostate cancer rises with age. Your risk also increases if a close family member (father or brother) has prostate cancer. The risk increases further if more than one close relative has prostate cancer, or if your relative was under the age of 60 when they were diagnosed. In the UK, African Caribbean men are three times more likely to develop prostate cancer than white men.

If you have any concerns about your prostate speak to your GP. You can also call the Prostate Cancer Charity Freephone Helpline Number: 0800 074 8383 (Monday to Friday 10am - 4pm & late night Wednesday 7pm - 9pm).

www.prostate-cancer.org.uk

Treatment

Prostate cancer may be localised (only affecting the prostate), or it may be locally advanced or advanced (the cancer has moved outside the prostate). If your doctors believe the cancer just affects the gland, they will discuss different kinds of treatment with you.

These could be:

- Active surveillance – where the state of the cancer is closely observed and treatment started only when, or if, necessary
- External Beam Radiotherapy – where radiation is used to kill cancer cells
- Surgery – where the prostate is removed
- Brachytherapy – where radioactive seeds are implanted into the prostate
- High dose rate Brachytherapy – Where temporary sources of radiation are targeted directly at the prostate.

Health and Wellbeing

Summer Health

SunSmart

Most of us love summer but it's important to protect yourself from the sun's harmful rays. Sun damage can cause skin cancer. More than 75,000 people in the UK are diagnosed with skin cancer each year. Sun damage happens when the sun's ultraviolet (UV) rays penetrate deep into the skin and damage cells. You can't feel this happening, and it can occur even when the sun doesn't feel very hot.

The SunSmart campaign suggests these simple steps:

- Spend time in the shade between 11am and 3pm.
- Make sure you never burn.
- Aim to cover up with a T-shirt, hat and sunglasses.
- Remember to take extra care with children.
- Then use factor 15+ sunscreen.

Report mole changes or unusual skin growths to your doctor as these can be a sign of cancer. Take special care not to burn, and be very careful with children.

Don't forget your eyes too! Sunglasses can also offer protection, but not all of them are adequate.

When you're shopping for sunglasses, choose a pair that has one of the following:

- the 'CE Mark' and British Standard (BS EN 1836:1997)
- a UV 400 label
- a statement that the sunglasses offer 100% UV protection.

More information on www.nhs.uk/livewell/summerhealth



What's On in June

16 May – 16 June National Smile Month www.nationalsmilemonth.org

1-30 Everyman male cancer awareness month - Everyman <http://everyman-campaign.org>

7-13 National glaucoma week - International Glaucoma Association www.glaucoma-association.com

7-13 National cervical cancer week www.jostrust.org.uk

12-20 National bike week www.bikeweek.org.uk

13-19 National epilepsy week - Epilepsy Action www.epilepsy.org.uk

13-19 Diabetes week - Diabetes UK www.diabetes.org.uk

14-20 Carers' week www.carersweek.org

14-20 National men's health week - Men's Health Forum www.menshealthforum.org.uk

14-20 Breathe easy week - British Lung Foundation www.lunguk.org

20 World osteoporosis day - National Osteoporosis Society www.nos.org.uk/NetCommunity/Page.aspx?pid=183

20-26 National Breastfeeding Week - NHS www.breastfeeding.nhs.uk

21-25 National falls awareness week - Age UK

www.ageuk.org.uk/get-involved/events-and-challenges/national-falls-awareness-week/?paging=false

21-27 Learning disability week - MENCAP www.mencap.org.uk

21-27 Deafblind awareness week - Deafblind UK www.deafblind.org.uk

LINK Steering Group and LINK Participant Meetings

7 Hospital Discharge Group 14.00-16.00

23 LINK Steering Group Meeting 12.15 – 14.30, Stanmer Room, BRIGHTHELM.

23 Out of Hours Action Group Meeting 18.00 – 19.15

1 July Mental Health Action Group 11.00-12.30

Complaints

Brighton and Hove is not a complaints service, we look at wider issues affecting people rather than issues that solely affect individuals. If you have a concern about an NHS service your first point of contact should be the Patient Advice and Liaison Service (PALS) at the relevant Trust. If you want to make a complaint but are unsure how to do this contact the Independent Complaints Advocacy Service (ICAS). They can help provide more information about the NHS complaints process and what it involves and provide support.

NHS Brighton and Hove PALS: 0800 013 0251

Brighton Sussex University Hospitals NHS Trust PALS: 01273 696955 ext 4029

ICAS: 01424 437491

Social Care: 01273 295555 (access point)

LINK Newsletter

Accessibility

We try to write this newsletter as clearly as possible. To ensure the information is accessible we:

- avoid jargon
- use plain English
- explain all acronyms
- provide easier to type links to webpages
- provide a telephone number, not just a website link
- produce the newsletter in other formats (on request)
- provide the newsletter as a download from the LINK website

Contributions

Brighton and Hove's LINK newsletter is issued every month, if you have an article that you would like considered for inclusion please email or post by the 20th of each month.

Making it better

We want to know how the newsletter can be better, we are always trying to improve. Let us know by contacting claire@cvsectorforum.org.uk

Saving Resources

After you have read the newsletter please forward on to anyone who you think would find it useful. Wherever possible we email the newsletter to save resources.

Disclaimer

The views expressed in this newsletter do not necessarily represent the views of the Brighton and Hove LINK. The LINK accepts no liability for any inaccuracies or omissions in this newsletter. Content of the newsletter is for general information.

Tell us what you think of health and social care services in Brighton and Hove and you could win £25 in M&S vouchers*. So not only will you help to improve local services but you will be in with a chance of winning £25.

**Each month we will select at random one individual who has given us their comments and award the prize.*



Linkadmin@cvsectorforum.org.uk

01273 810 235

You can also text us on 07833 591795

You can now follow us on www.twitter.com/bhlink and

Facebook - Brighton and Hove LINK.



Freepost RSGY-UXAC-ZZZG

Brighton & Hove Local Involvement Network

BRIGHTON

BN1 4GQ

What does it mean?

A glossary of health and social care terms

Advocate	a person who supports someone and can act on their behalf
Clinical	of, or for, the treatment of patients
Commissioning	the means by which the best value is secured for local citizens and taxpayers ie the best possible health and wellbeing outcomes, and health and social care provision, within the resources available
Health provider	an organisation which offers services to improve people's health
Intermediate care	alternative to general hospital admission for treatment. Also provided to allow patients to be safely discharged from hospital & complete their recovery at home or other suitable place, such as a community hospital or nursing home
Joint commissioning	usually refers to NHS and social services working together to agree spending plans to get the best service for those who use their services, such as mental health service users, physically disabled people, older people
LINK Action Group	a small group of people who meet to discuss issues and agree actions on a defined topic
LINK Steering group	the group of 15 elected people who lead and coordinate the activities of the LINK (Local Involvement Network)
NHS	National Health Service
NHS Trust	could either be a commissioner or a provider trust. Primary care trusts are often both commissioners & providers
PALs	Patient Advice Liaison Service – an in house service providing information & help to NHS patients
Primary care	care provided by GP's and the team who work with them in their surgeries, health centres & by dentists, pharmacists & opticians
Primary Care Trust (PCT)	the main commissioning body in the NHS. PCT's have replaced health authorities. The PCT in Brighton & Hove is now called NHS Brighton and Hove
Providers	Hospital Trusts, GP's voluntary organisations & sometimes private institutions who provide health care according to their contract with the PCT
Social care provider	an organisation which offers services to help support people

Providers in Brighton and Hove

Brighton & Hove City Council (BHCC)	provides Social Care Services (commonly known as Social Services) to protect, care for and support vulnerable people to enable them to live as full and independent lives as possible.
Brighton and Sussex University Hospitals (BSUH)	regional teaching hospital ; provides general and specialist acute hospital services working as one teaching hospital across two sites, Royal Sussex County Hospital and Princess Royal Hospital
Children and Young People's Trust (CYPT)	brings together education, health and social care for all 0-19-year-olds (and up to 25 years for those with special needs)
South Downs NHS Health Trust (SDHT)	provides community, rehabilitation, specialist and, in co-operation with the Children and Young People's Trust, children's services for people living mainly in the Brighton and Hove area
South East Coast Ambulance Service (SECAMBS)	responds to 999 calls from the public, urgent calls from health professionals and in Kent and Sussex, and provides non-emergency patient transport services
Sussex Partnership NHS Foundation Trust (Sussex Partnership)	provides specialist mental health, learning disability and substance misuse services in and across Sussex.