

Welcome to the December 2011 edition of the SIGN Patient Newsletter



New publications from SIGN

Management of asthma: patient versions

SIGN worked with Asthma UK to develop patient versions of the BTS/SIGN British guideline on the management of asthma. The booklets, one for adults and one for children have been developed to help, support and empower patients to self manage their asthma.



The booklets cover:

- ★ diagnosis;
- ★ assessment and monitoring;
- ★ medicines used to treat asthma;
- ★ acute asthma;
- ★ adolescent asthma;
- ★ self management; and
- ★ details of where to get more information.





The patient versions were launched on 8th December at the British Thoracic Society (BTS) winter meeting in London. Asthma UK's clinical lead Cher Piddock gave a presentation highlighting the aims of the patient versions and discussed how healthcare professionals should use these as a tool to help patients to become more involved in the management of their asthma.



Patient representative Mike McGregor gave a talk on what the patient booklets will mean for people with asthma and how they can help them to become more involved in the management of their condition. If you would like copies of the patient versions, please let me know.

Alternative formats of patient versions

SIGN has now produced the ASD booklet for parents and carers in Gaelic and has produced the patient version of the psoriasis and psoriatic arthritis guideline in Urdu. If you work with people who could benefit from these booklets, they are available for download from our website

www.sign.ac.uk/patients/publications.html



SIGN Awareness Volunteers

David Paul: an appreciation

We were very sad to hear of the recent death of David Paul one of SIGN's awareness volunteers and a stalwart of true patient involvement. David has been involved with SIGN for more than a decade in a variety of different ways, including:

- ★ guideline group member for the original and revised diabetes guideline (and patient version)
- ★ peer reviewer for stroke assessment, chlamydia and VTE guidelines
- ★ lay reviewer for all patient versions
- ★ Awareness Volunteer since 2009, which included giving talks to student nurses at Glasgow Caledonian and Abertay Universities, arranging and exhibiting at Perth Royal Infirmary and the Royal Infirmary of Edinburgh and giving talks to support groups such as the Gartnaval diabetes group.

David also mentored and supported other patient representatives. SIGN is very grateful for David's contribution and he will be sorely missed. Our thoughts go out to David's wife Lorna and his family.



Welcome to our new volunteers

I mentioned in the last edition of the newsletter that we would be recruiting more people from various areas in Scotland.

I would like to welcome our three new Awareness Volunteers to SIGN: Robert Bell, Dianna Manson and Anna Hart – we look forward to working with them!

Awareness raising activities

Our volunteers have been busy carrying out activities over the past six months to raise awareness of SIGN. Some of the activities include:

- ★ giving a talk to student nurses at Glasgow Caledonian University
- ★ distributing flyers to raise awareness of the SIGN app
- ★ hosting an exhibition stand at the WISH conference
- ★ hosting an exhibition stand and networking at Bipolar Scotland conference
- ★ hosting an exhibition stand at Modelling the biological and psychological markers of health behaviour change conference
- ★ giving a talk to students nurses at Abertay University
- ★ giving a talk to Glasgow South diabetes support group
- ★ hosting an exhibition stand at UKSMB 7th Annual Scientific meeting

If you are a member of a community group or health organisation and would like one of our volunteers to visit your organisation to tell your members about SIGN, please let me know. We can also arrange for you to visit SIGN to hear from our volunteers if you prefer.

Do you have time to sit on a guideline development group?

SIGN will begin to review the following guidelines at the beginning of 2012:

- ★ epithelial ovarian cancer; and
- ★ diagnosis and management of epilepsy in adults.

We are in the process of recruiting patient/lay representatives to these groups. Membership of a guideline development group provides an opportunity for patients' and carers' voices to be heard so please help us to get people involved.

If you would like to find out more about what group membership would entail, please get in touch with me and I can send out the information pack.

Do you have time to review a draft patient version of the guideline on perinatal mood disorders?

We are now consulting on the patient version of the guideline on perinatal mood disorders and are looking for lay representatives to take part in the process.

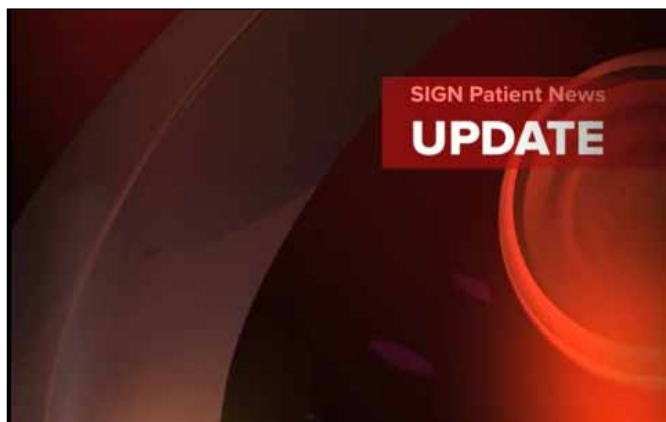
Perhaps you have experience of postnatal depression or postpartum psychosis or know someone who has? Perhaps you don't have experience of perinatal mood disorders but have an interest in women's mental health?

If you think you can help, please get in touch with me.



SIGN Patient podcast on YouTube

SIGN now has its own channel on YouTube and launched it with the June edition of the SIGN patient newsletter. All editions from now on will be available as patient news podcasts.



The podcast is available at www.youtube.com/user/SIGNGuideline

SIGN wins first prize for Best NHS Scotland use of mobile technology in NHS Scotland

In the last edition of the newsletter I mentioned that SIGN recently launched an app for the iPhone, iPad, and iPod touch, and Android phones and tablets. At the recent eHealth Awards in Edinburgh, the SIGN app won the first prize for the Best use of mobile technology in NHS Scotland.



Sara Twaddle, Stuart Neville and Roberta James of SIGN

Accepting the award at a ceremony at the Royal College of Surgeons of Edinburgh, Sara Twaddle, Director of SIGN said, 'SIGN are delighted to receive this award. The app is only as good as the information it contains and we are grateful to the many hundreds of healthcare professionals throughout NHSScotland whose work on developing the guidelines has provided this content.

We are hopeful that providing information in the way will help healthcare professionals have access to evidence based recommendations at the point of contact with patients'.



In production: iPhone, iPad and Android app for patient guidelines

SIGN has started production of an app for patient versions of guidelines. The first patient app will be autism spectrum disorders (ASD) in children and young people.



The ASD booklet has been an extremely popular; healthcare professionals use it to make young people and their families/carers aware of the treatment and care they should expect to receive. They also use it to help young people and their families/carers to take control of their condition by understanding the latest research evidence.

The app will be available for download from the Apple App Store and Andriod Market early in 2012..

Involving patients in the review of the schizophrenia guideline

SIGN is currently reviewing the guideline on management of schizophrenia. In addition to having two carer representatives on the guideline group, we decided to run a focus group in September with service users.

The focus group aimed to hear about their experiences of mental health services in relation to information provision. The people who contributed were a selected sample but their perspectives emphasise the need for adequate information provision and the importance for the involvement of patients and carers in discussions.

The key messages from the focus group informed the checklist in the 'provision of information' section of the guideline.

We had further patient input to the guideline development process by inviting service users from the Consultation and Advocacy Promotion Service (CAPS) to speak at the national opening meeting in November about their experiences of psychosis and to hear their views on what would be helpful to patients when being treated.

The talks were very well received by healthcare professionals who appreciated them sharing their experiences to highlight the issues that are important to patients and carers. We are grateful to the service users for sharing their experiences with delegates.

Involving patients in brain injury rehabilitation national open meeting

On 5th December, SIGN held a national open meeting to consult on the draft guideline on brain injury rehabilitation.

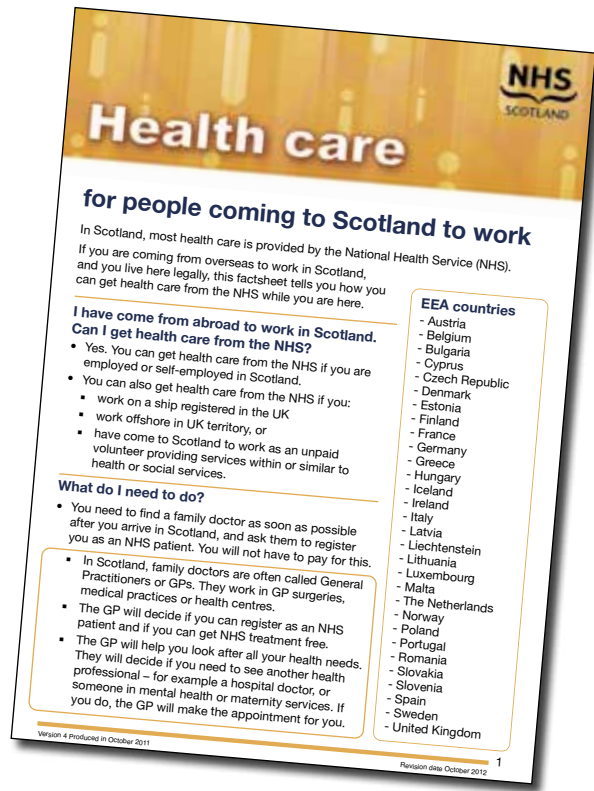
We invited Kevin Whitworth from the Isle of Lewis to set the scene at the meeting by giving his story "What happened to me". Kevin had an accident in August 2010 whilst kayaking and has been receiving rehabilitation ever since. Kevin was in a coma for a few months in Southern General Hospital and was then transferred to Murdostoun Brain Injury Rehabilitation Centre when he was minimally conscious. He was unable to speak, move or eat for sometime.

Kevin spoke about the benefits of rehabilitation and what he has managed to achieve by this. He also talked about the importance of keeping patients and carers informed.

Kevin was very positive and hopeful for the future - he uses a diary at the moment but he is hopeful that his memory will improve. He is also hopeful that with more physiotherapy he will be able to walk again.

We would like to thank Kevin for sharing such a powerful and moving story with delegates and we wish him well for the future with his partner Jenny.





New information from Healthrights Information Scotland (HRIS)

Health Rights Information Scotland (HRIS) have just published the revised version of seven factsheets explaining the circumstances under which particular groups of overseas visitors are entitled to NHS care in Scotland.

The revised entitlements factsheets are called:

- ★ Health care for people coming to Scotland to work
- ★ Health care for people coming to Scotland to study
- ★ Health care for asylum seekers and refugees in Scotland
- ★ Health care in Scotland for former UK residents now working abroad
- ★ Health care in Scotland for UK passport holders living abroad
- ★ Health care for UK pensioners visiting Scotland
- ★ Health care in Scotland for holidaymakers from overseas.

HRIS have published all the factsheets in the Health care for overseas visitors section of their website (www.hris.org.uk) where they are available in a variety of formats, including large print, translated versions in a number of languages, English audio versions, translated audio versions (information for asylum seekers and refugees only), and British Sign Language (BSL).

Events organised by other people

*WISH national conference • 25th January
Stirling Management Centre*

As recognised within the Sexual Health and Blood Borne Virus Framework (2011 - 2015), self-esteem and aspiration have an important role to play in ensuring that sex takes place within a safe, respectful and mutually supportive environment and that sexual experiences are not coerced or regretted.

It is important that all young people should be supported through programmes of confidence, self-esteem and aspiration building.

The conference will examine the evidence of US based youth development programmes and delegates will have the opportunity to consider their transferability to a Scottish context.

WISH aim to limit travel and widen access to this year's conference by using an online virtual method. Once registered, you will be able to view the conference from your work or home computer.

Please register your interest now at www.regonline.co.uk/wishnationalevent.

The conference programme is available to download from the registration site.



*Living with Long Term Conditions:
Employability, Poverty and Welfare Reform
27th March • Glasgow*

The aim of this event is to explore key issues and good practice in addressing employability and financial inclusion for people living with long term conditions.

Themes will include:

- ★ Policy context (Scottish and UK)
- ★ Equality of access to employment and the impact of inequality
- ★ Addressing barriers to (good) employment
- ★ Support for individuals to gain and retain employment
- ★ The role of employers
- ★ Links with key agendas including self management, self-directed support, human rights and independent living

For more information visit www.ltcas.org.uk/news-and-events/events/date/1332806400/



I would like to thank you all for the contributions you have made to SIGN during 2011.

I hope you all have a good Christmas and I look forward to working with you in 2012.

