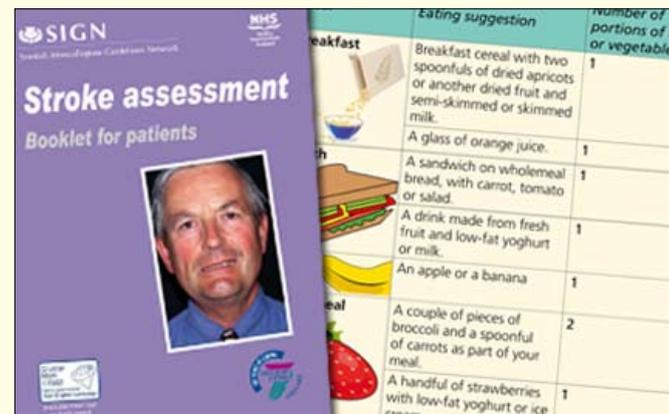


*Welcome to the SIGN patient network update*

## New SIGN Publications

### Management of patients with Stroke or TIA: assessment, investigation, immediate management and secondary prevention

The SIGN guideline on Management of patients with Stroke or TIA: assessment, investigation, immediate management and secondary prevention was launched last December. At the launch event, a co-ordinated package of care for stroke patients

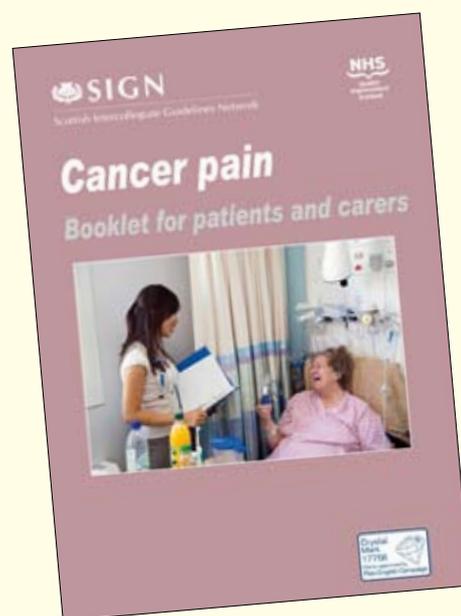


in Scotland was presented including:

- the SIGN guideline
- a patient version of the SIGN guideline that translates the clinical recommendations into a user friendly booklet
- updated clinical standards for care of stroke patients in the acute setting
- a budgetary impact assessment of the key recommendations
- national key performance indicators in acute stroke showing patients and carers what care, support and information to expect immediately after a stroke.

At the launch, Chest Heart and Stroke's Health Information Manager Lorna McTernan gave a presentation on the development of the patient version. This presentation outlined the aims of the patient version, highlighted how content was decided and gave an overview of the development process. If you were unable to attend the launch, you can view the presentations from our website at [www.sign.ac.uk/guidelines/fulltext/108/index.html](http://www.sign.ac.uk/guidelines/fulltext/108/index.html)

Copies of the stroke guideline or patient version can be requested from [nicola.aitken@nhs.net](mailto:nicola.aitken@nhs.net)



### Control of cancer pain in adults

On World Cancer Day, 4<sup>th</sup> February, SIGN launched the patient version of Control of cancer pain in adults. We worked with the Patient Information Centre at the Royal Infirmary of Edinburgh to promote World Cancer Day and raise awareness of the new patient version.

A number of patients and staff spoke to us about their experience of cancer; they told us that they or people they knew were experiencing pain associated with cancer but were receiving no treatment. I hope that our patient booklet will encourage people to tell their healthcare professionals that they have pain and to ask about the treatments that are available.

If you are interested in receiving copies of the patient version, which is also available in Large Print please contact [nicola.aitken@nhs.net](mailto:nicola.aitken@nhs.net)

# New look for Patient involvement section of SIGN website

I mentioned a while ago that we were planning on revamping the patient involvement section of the SIGN website and I'm delighted to tell you that work is now underway.

Our patient representatives have been helping us to decide content, layout and have been looking at how we can make our site more user-friendly and interactive. We hope that by making our website more interactive, we can involve a wider range of people in our work.

## SIGN patient representatives help to guide the way to our guidelines

In December, we invited our patient representatives along to a discussion day to explore how they could help SIGN to raise awareness of the organisation and its guidelines.

Patient representatives came up with ideas including helping with exhibition stands at events, giving talks to patient groups they are involved with and giving talks to medical and nursing students on the importance of SIGN guidelines and patient versions.

Since our patient representatives were so enthusiastic about helping us with awareness raising and dissemination initiatives, we have decided to set up a new patient dissemination group. The group will have the following aims:

- Actively identify awareness raising opportunities and advise the Patient Involvement Officer of these.
- Participate in awareness raising activities, for example by giving talks at medical/nursing conferences, as well as to students, voluntary groups and patient groups.
- Work with Community Health Partnerships/Public Partnership Forums to raise awareness of SIGN's work.

- Identify groups to distribute guidelines, patient versions and information leaflets to and help them to distribute to relevant groups they are involved with.
- Contribute to advertising materials such as leaflets and posters
- Highlight patient issues of concern which arise from awareness raising activities.
- Support lay representatives on guideline development groups who participate in awareness raising activities.

We will be recruiting for this group shortly but if you would like to express an interest in this group, let me know and I can send you further information and nomination forms when we start the recruitment process.

## What's on at SIGN

We would like to give you advance notice of the following national meetings.

- *Prophylaxis and treatment of deep vein thrombosis and Management of patients on antithrombotic therapy.* A joint meeting on **Friday 25 September 2009, Royal College of Physicians, Edinburgh**
- *Management of atopic eczema and Management of Psoriasis and Psoriatic Arthritis in Adults.* A joint meeting on **Thursday 1 October 2009, Our Dynamic Earth, Edinburgh**

At these meetings the guideline development groups will present their draft recommendations and will be looking for feedback.

If you have been affected by any of these conditions, I would encourage you to come along as this is your chance to make sure that the guidelines have taken account of the matters that are important to patients and carers.

If you can't make the meetings but would still like to comment on the draft guidelines, let me know and we can send you a copy.

## In development - patient version of non-pharmacological management of depression

In February, we started developing the patient version of the guideline on non-pharmacological management of patients with depression. This patient booklet will cover:

- What depression is;
- What treatments and information are available; and
- What patients can expect from treatments.

We anticipate that this booklet will be available for consultation by the summer. If you would like to be involved in the consultation, please let me know. You can comment on the draft as an individual or as a member of any patient group you belong to. We can come along and work with you in a group setting to collect feedback.

## Do you have time to review a draft guideline?

We have a number of guidelines that will be due for consultation in the forthcoming months and we are looking for lay reviewers to comment on them from a patient perspective. You don't need to address every aspect of the guideline but can comment on the areas where you feel your expertise is most relevant. If you would like to review any of the following guidelines, please let me know.

- Non-pharmacological management of depression
- Pharmacological management of Parkinson's disease
- Management of obesity in adults and children

## Events organised by other people



### Transitions conference 2009: moving out, moving on – but where to? 21<sup>st</sup> April, Westerwood Hotel, Cumbernauld

This is a national dialogue to explore the transitional requirements of young people with special needs. The conference will examine a number of themes including :

- Young people moving on from residential care and education
- Identifying changing trends in individual needs and potential future provision
- Managing the search and transition process - including resource issues and the role of self-directed support
- Engaging the parents, young people, current placements, potential new provisions, local authorities and health services
- Coping with settling in and worrying about no way back

For more information visit [www.shsc.scot.nhs.uk/upload/file/conventions/kinharvie/final\\_flyer.pdf](http://www.shsc.scot.nhs.uk/upload/file/conventions/kinharvie/final_flyer.pdf) or phone 0131 275 7748

### Epilepsy: Psychological and social well-being, 14<sup>th</sup> May • Apex International Hotel, Edinburgh

This conference aims to examine the links between epilepsy and mental health; understand the needs of people with epilepsy in order to maintain good mental health and examine the service pathway for people with epilepsy and mental illness in Scotland. This is a full day event with speakers from neurology, psychiatry, neuropsychology, academia, nursing and the voluntary sector.

For more information, please visit [www.epilepsyscotland.org.uk/news\\_events/news/newsarticles/psychological\\_conf.html](http://www.epilepsyscotland.org.uk/news_events/news/newsarticles/psychological_conf.html) or phone 0141 427 4911.

## Changing Faces Reach Out Workshop 11<sup>th</sup> June, Glasgow, venue to be confirmed

This workshop is organised by the charity Changing Faces, which offers information and support to help people deal with the challenges of living with a visible difference.

This small group workshop provides the opportunity for you to explore in a safe space some common concerns around appearance and interactions with others and find new ways to deal with them.

For more information or to apply, contact:

Gareth Jenkins, Changing Faces Scotland Officer:  
0845 4500 640 or [Scotland@changingfaces.org.uk](mailto:Scotland@changingfaces.org.uk)

## Health Awareness



### World Autism Awareness Day 2<sup>nd</sup> April 2009

To mark the United Nations' World Autism Awareness Day, Autism Speaks UK is proud to be working alongside other autism charities in the UK to generate a greater understanding of autism and call for people to Stand Up for Autism.

For more information visit  
[www.worldautismawarenessday.org](http://www.worldautismawarenessday.org)



SIGN now has the patient versions of Autism Spectrum Disorders in Polish and Urdu. If you work with groups who could benefit from these booklets, please let me know.

### National stop snoring week 20<sup>th</sup> April - 25<sup>th</sup> April

The British Snoring and Sleep Apnoea Association aim to promote public awareness that snoring and sleep apnoea are generally treatable complaints and that help is available. They offer a range of information on the causes and treatments. For more information visit, [www.britishsnoring.co.uk](http://www.britishsnoring.co.uk)



### SANDS (Stillbirth and Neonatal Death Society) Awareness Month - June 2009

SANDS is a long established UK charity that supports anyone affected by the death of a baby during pregnancy or after birth. SANDS works with health professionals to improve the quality of care provided to bereaved families and promotes research and changes in practice to reduce the loss of babies' lives.

For more information, visit [www.uk-sands.org](http://www.uk-sands.org) or phone 020 7436 7940

# Launch of the King's Fund Point of Care programme

In early December, the King's Fund Point of Care programme was launched. The programme aims to improve the experience of care for patients and their families, starting with acute care in hospitals. Taking a systems-wide approach, their goal is to enable staff to deliver the quality of care they would want for themselves and their own families.

Point of Care is working with senior leaders to achieve the changes in culture and management that are needed, and developing methods to support all staff to deliver care. For more information see: [www.kingsfund.org.uk/current\\_projects/the\\_point\\_of\\_care/index.html](http://www.kingsfund.org.uk/current_projects/the_point_of_care/index.html)

The Point of Care Programme report looks at some of the problems that patients experience with their care and at the factors that shape that experience. The report assesses the evidence to support interventions to improve patients' experience, and suggests initiatives that have the potential to create sustainable change in the quality of patients' care.

The full report can be downloaded from [www.kingsfund.org.uk/publications/the\\_kings\\_fund\\_publications/the\\_point\\_of\\_care.html](http://www.kingsfund.org.uk/publications/the_kings_fund_publications/the_point_of_care.html)



## Informing patients about ways to comment or complain!

Health Rights Information Scotland (HRIS) has launched a new poster to tell patients how to give comments, express concerns or complain about NHS care and treatment.

Help your NHS get it right! promotes the availability of the leaflet Making a complaint about the NHS and encourages patients to communicate with the NHS. Members of the NHS Complaints Personnel Association Scotland, members of the Patient Information Network and other NHS staff have all been involved in the development of the posters.

NHS boards throughout Scotland have been given a supply of the posters for distribution to places within their area that provide NHS care. This includes hospitals, GP and dental surgeries, and pharmacies. Help your NHS get it right! is also available from the HRIS website at [www.hris.org.uk/index.aspx?o=1113](http://www.hris.org.uk/index.aspx?o=1113)

For more information, please contact Brigitte Cosford, HRIS Support Officer (email [brigitte.cosford@consumerfocus-scotland.org.uk](mailto:brigitte.cosford@consumerfocus-scotland.org.uk) or phone 0141 227 8440).

# Take part in the 'Hear Me 2' survey



'see me' is Scotland's national campaign to end the stigma and discrimination of mental ill-health. They have just launched their second national survey 'Hear Me 2'.

This survey aims to gather detailed information about the ways in which stigma affects those with lived-experience of mental health problems. It is the only national survey of its kind in Scotland and aim is to reach people across the country.

One in every four of us is likely to experience some kind of mental health problem, and they want to get to the very heart of how and where stigma and discrimination happen.

The survey will give 'see me' valuable information to help the campaign decide where it should target its efforts in future. It has also been designed to find out whether those directly affected by stigma think that 'see me' is making a difference where it really matters; in people's behaviour towards them.

The survey, which will run until the end of May 2009, can be easily completed by visiting the 'see me' website at [www.seemescotland.org](http://www.seemescotland.org). You can also order hard copies of the survey direct from 'see me' by phoning 0131 554 0218, or by emailing [info@seemescotland.org](mailto:info@seemescotland.org)

Best wishes

A handwritten signature in black ink that reads 'Karen Graham'. The signature is written in a cursive, flowing style.