



Patient News Update

Summer 2013

New publications from SIGN

Long term follow up of survivors of childhood cancer

This guideline applies to all people who have survived cancer in childhood, and who may experience late effects that are related to the treatment received.

Brain injury rehabilitation in adults



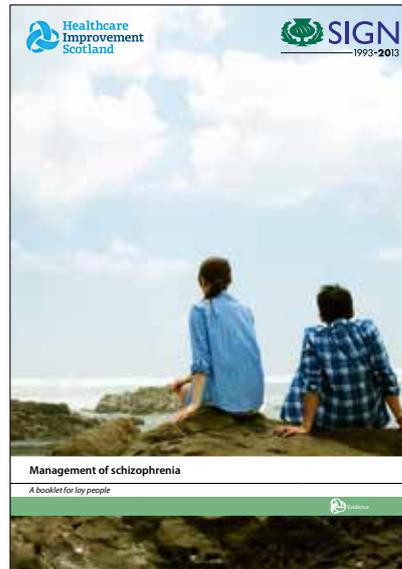
The new guideline covers:

- ★ assessment and treatment of mild brain injury;
★ physical rehabilitation and management;
★ cognitive rehabilitation;
★ rehabilitation of behavioural and emotional disorders;
★ communication and swallowing; and
★ vocational rehabilitation

Management of schizophrenia in adults

This revised guideline covers:

- ★ dual diagnosis;
★ access and engagement;
★ pharmacological interventions;
★ psychological therapies; and
★ perinatal issues.



Both of these guidelines will have accompanying patient versions which will be available in August. We received a huge number of comments from patient network members on the consultation drafts of these patient versions.

We would like to thank you for taking the time to review these documents – your comments really do make a difference.

If you would like copies of any of the above patient versions, please e-mail gemma.hardie@nhs.net

Patient versions of guidelines

Patient versions in development

We have recently started to revise the patient version of the lung cancer guideline.

We also plan to develop a patient version of the new chronic pain guideline. We anticipate that these patient versions will be available for consultation in September.

These draft documents will be sent to all patient network members by e-mail and if these are topics that you have experience of or are interested in, we would welcome your comments. If you would like hard copies of these documents, please let me know.



Alternative formats of patient versions

Perinatal mood disorders

This patient version is now available in Urdu, Mandarin and Polish and can be downloaded from our website.

Autism Spectrum Disorders

The patient version which has been written for parents and carers is currently being translated into Russian.

Managing asthma in children

This patient version is currently being translated into Polish. If you know people who speak any of the above languages and who could benefit from these booklets, please let them know about them.

SIGN Awareness Volunteers

Awareness raising activities

As well as giving talks to community groups, SIGN's awareness volunteers are continuing to exhibit at conferences and events on SIGN's behalf. Some of the activities the volunteers have been carrying out or have planned include:

- ★ Hosting an exhibition stand at the Autism and Action event, University of Aberdeen
- ★ Hosting an exhibition stand at the Ageing Society event, University of Aberdeen
- ★ Raising awareness of the consultation draft the schizophrenia patient version with local mental health support groups
- ★ Updating Orkney NHS Public partnership Forum on SIGN's work

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 the SIGN office to hear from our volunteers if you prefer.

Are you interested in becoming an Awareness Volunteer?

SIGN would like to recruit two more lay representatives to become proactive Awareness Volunteers. Perhaps you have been commenting on guidelines and patient versions for years and would like to become a bit more involved with sharing SIGN's good work?

Have you represented patients on a guideline development group in the past and would like to make people aware of the work SIGN does? Do you have access to good networks that you think would be interested in hearing about SIGN?

If you think you can help, please get in touch with me and I will send you out an application form.

Welcome to our new lay representatives on SIGN Council!

SIGN would like to welcome our new lay representatives to SIGN Council. Eileen Wallace and Suzanne Clark have been involved in SIGN and Healthcare Improvement's patient and public involvement activities for many years. This will be an exciting and challenging opportunity at SIGN.

Investing in Volunteers award

Our organisation gained the iV award in 2010 for a period of three years. Investing in volunteers is a quality standard that demonstrates a commitment towards volunteer development within an organisation.

The award sets out a level of practice which organisations should meet in order to ensure quality, effective and safe opportunities for volunteers. It is now time for the organisation to be reassessed.

A development group consisting of staff and volunteers from NHS Healthcare Improvement Scotland will work together to ensure that the organisation is sustaining the good practice. As a result some policies and methods relating to volunteers will be reviewed, refreshed and communicated to staff and volunteers.

Care of people with multimorbidity

A collaboration between NICE and two academic teams will support a time limited project looking at ways of providing better clinical guidelines concerning the care of people with multimorbidity - that is people who have more than one chronic illness.

This project seeks to develop innovative ways of using evidence and creating guidelines to make them better able to improve care for this group.

There was a huge response from lay representatives to take part in this project and I would like to thank individuals from SIGN's patient network who expressed an interest in taking part.

All applications were considered by NICE who selected one lay representative from SIGN's patient network. I will keep network members updated with progress by this group.



SIGN

1993-2013

20 years of SIGN

This year marks SIGN's 20th anniversary. SIGN was one of the first national programmes of evidence based clinical practice guidelines and plays a leading role in guideline methodology developments at an international level.

SIGN has always valued the input of patient and carer involvement in guideline production but the patient involvement programme has evolved significantly in recent years. In 2007 the first series of patient versions of guidelines were published - SIGN has published 18 patient versions to date.

SIGN 100 – a patient version of the guideline developers manual was published in 2008 and has proved to be a vital tool to allow patients and carers to gain the knowledge necessary to take part in guideline development.

In 2010, SIGN made a commitment to involving patients and carers in all aspects of guideline activity. A group of patients and members of the public were recruited to have a role in SIGN's dissemination and implementation strategy.

SIGN is proud of the achievements in patient and public involvement over the years and will continue to develop the patient and public involvement programme.

SIGN lay representative to publish book on her experience of mental illness

Tina mentioned to me in a conversation that she had been writing a book on her experiences of an eating disorder and psychosis.

She chose to write a book to help others who experience mental health problems and to dispel some of the myths and shame that surround mental health.

I asked Tina if she would mind sharing her story with Patient Network members and she agreed to share the first chapter of her book which I found very moving. Her book is with an agent at the moment and she expects it to be published this year.

Seconds to snap, years to recover by Tina Halford-McGuff

"I'm a very happy woman today ... and a very lucky one. I have a wonderful husband and my children are healthy and happy, something that I a few years ago I could never even have dared to wish for.

Then there was no hope let alone a dream of a happy future. I was trapped in the horrific reality I was living in at the time. But I was very fortunate that a number of committed health professionals literally saved my life and rescued me from a vicious downward spiral of self-destruction.

At 13, I found myself catapulted out of the most idyllic and very innocent life with what I thought were perfect parents, a perfect house and happy sisters into the worst childhood I could have asked for. I turned to substance abuse, smoking, and alcohol as methods to control my pain, anger and mental anguish. I could never have imagined that over the next 7 years of my life my beautiful mum would end up in jail and that I would be sectioned under the mental health act and sent to an adult psychiatric unit as a sixteen year-old.

As anorexia nervosa steadily tightened its evil grip on me, I stopped eating and nearly starved to death after my weight dropped from a healthy 9 stones down to a skeletal 4 stone. I was a sack of bones encased in a parchment of paper-thin, dried out skin and close to death. Little wonder that a complete nervous breakdown followed.

In my early 20s I suffered a severe episode of psychosis where I ended up in another secure unit of a psychiatric unit and given various medications with strange side effects to try and help me. I required intensive psychiatric treatment from excellent doctors. It all helped and I have never been affected in over 20 years now.

They ensured that I have been able to lead a fulfilling and productive life. I chose to write a book not only to thank those who helped me but also to dispel the myths and the shame that surround mental health problems. This book is with an agent at the moment.

Until the age of 30 those feelings of shame compounded my illness. Then I understood that it's not what people think of you that matters and realised the truth of the old saying: 'Those who matter don't mind and those who mind don't matter.'

Today I have friends and acquaintances that battle daily with mental health issues and are too scared to go to the doctors or get help for fear of the stigma. They are scared that if their employer finds out they will be fired or be deemed unemployable or that friends will think they are 'cuckoo'. There are so many urban myths surrounding eating disorders. It is wrong and has to change for the benefit of all".

Have you been sent this newsletter via a friend or a colleague? Why not join the SIGN Patient Network yourself and you will receive an e-mail with the link to the newsletter on the day it's published? Join today at www.sign.ac.uk/pdf/patient_join_form.pdf

I hope you all have a lovely summer



Karen Graham