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For everyone concerned with stroke rehabilitation

A new approach to self-care

Stroke is the most complex and prevalent disability in the UK, affecting over 130,000 people in England and Wales alone. In the UK, stroke costs £4.2 billion per annum in terms of lost productivity, disability and informal care costs.

The **Stepping Out** programme is a new approach to working with stroke survivors and supports the development of effective self-management skills and aims to work with and compliment existing stroke services.

Improving self-care is a major focus of policy and service development in the UK and Stepping Out aims to align with current recommendations on improving self-care for individuals with chronic diseases. The programme incorporate the current best available evidence on patient-focused interventions.

A key publication which summarises the best available evidence on patient-focused interventions was carried out by Angela Coulter and Jo Ellins from the Picker Institute. Published in August 2006, it is available at www.health.org.uk/qquip.

The key recommendations include improving:

- health literacy
- clinical decision-making
- self-care
- patient safety
- access to health advice
- the care experience
- service development.

An article published in *Social Science & Medicine* in 2007 by Kendall and colleagues is one of the first to present the results of a randomised controlled trial involving 100 people with stroke that were randomly allocated to a self-management intervention based on self-efficacy principles.

The intervention group avoided a decline in functioning in the first year which were reported by the control group, and the intervention may have provided individuals with more positive ways of coping with the transition phases of being discharged from hospital or therapy services.

The Stepping Out Workbook

The workbook is specifically designed to help stroke survivors to manage their stroke.

It enables users to set targets and record successes and to read about other stroke survivors and the strategies they have used in their own rehabilitation.

Section 1: personal stories from different individuals who have faced a variety of difficulties after stroke.

Section 2: examples of common problems faced by these individuals and how they managed to resolve them.

Section 3: examples of activities and exercises which have been developed into a personal home exercise programme.

Section 4: designed to encourage the user to make personal targets and record progress on a daily basis.



steppingout

a stroke self-management programme enabling individuals to take control of their daily lives



What progress has been made

Phase 1: Pilot studies and evaluation

At the end of June 2007 the **Stepping Out** programme had been evaluated by three UK stroke rehabilitation services. Earlier this year interactive workshops were held in three pilot sites at Inverness, Sutton and Merton, and Christchurch, with therapists and nurses involved in all stages of the stroke journey (acute and community services). A total of 45 practitioners working in stroke attended over the three sites. The results of these pilots have now been collated and analysed.

Workshop participants were introduced to the Stepping Out workbook and practised methods of interactive problem-solving and target-setting using the workbook in order to encourage successful self-management. A number of workbooks were provided for participants to use with clients on their caseload, and a resource pack was provided to support the topics covered in the workshop.

In May this year the therapy teams in these three locations were revisited and further feedback gained on

the value of implementing the Stepping Out programme. This was achieved through focus-groups with the therapy teams.

The phase 1 evaluation shows widespread support for the Stepping Out programme with most practitioners committed to embedding it in their own practice, and making it available for individuals who have had a stroke when the programme is launched in 2008. What is also apparent, though, is the need for professionals to understand, and believe in, the theory of self-management before they start using Stepping Out. Spending time with individuals who have had a stroke, supporting them to set targets and then reflect on their success, may be a new way of working for many.

Project Leader, Dr Fiona Jones, is now reworking the workbook to reflect constructive comments from the pilot studies. Questions raised at the sites are also being addressed by the advisory group. For example:

- At what stage in the patient journey is it appropriate to introduce Stepping Out?

How does Stepping Out work

Stepping Out consists of three components:

- **Training:** an individualised self-management training programme for stroke survivors and their carers.
- **Workbook:** an interactive workbook for stroke survivors which supports the training programme.
- **Workshops:** a complementary programme (workshop, follow-up support, and resource pack) designed for practitioners working at

all stages of the stroke journey, enhancing their skills to be able to deliver self-management training.

Stepping Out has been developed through extensive consultation with stroke survivors, carers and relevant professionals and is based on an emerging body of research that has been carried out on self-care interventions for individuals with other chronic illnesses.

The underpinning theoretical basis is Banduras's self-efficacy.

A more holistic, more patient-orientated, enhanced approach to self-managed rehabilitation after stroke.



- Which professionals should deliver Stepping Out?
- To what extent will it be possible to adapt Stepping Out to fit local practice?

These are just a few of the many questions that are being addressed right now.

Thanks are due to the therapy teams, patients and carers at these three sites for their enthusiasm and constructive feedback between January and June this year.

Phase 2: Gearing up

By late 2007 the workbook and training materials will have been rewritten and redesigned in response to the feedback gained in Phase 1. Research to demonstrate the cost-effectiveness of Stepping Out will have commenced and the Stepping Out team will be supplemented by further professionals, including a health economist, a psychologist, an occupational therapist and a carer.

We will have defined at what stage Stepping Out should be made available to the patient. The key competencies and roles of the trainers who will deliver the programme will be established and, in early 2008, we will recruit our first five trainers (information will be available on the website and in the next edition of Stride).

Throughout 2008 we will be approaching commissioners with information about Stepping Out and explaining how they can purchase the programme. Training sessions are likely to be 2 days and cost approximately £250 per trainee. This includes five copies of the workbook and follow-up support after the training course. Individuals and Trusts can register their interest now by contacting Dr Fiona Jones at fjones@hscs.sgul.ac.uk.

We expect to be present at the UK Stroke Forum with a stand in November this year and have already started to foster strategic links with key charities and professional organisations in the stroke field.

Our structure will change. At present Stepping Out is hosted within the Faculty of Health and Social Care at St George's University of London. In the coming months we will become a Community Interest Company (CIC). A CIC is a social enterprise which exists solely to provide benefit to the community.

All activities, therefore, and any profits, must be directed at benefiting individuals who have had a stroke, their carers and their families. This arrangement will perfectly reflect the aims and objectives of Stepping Out.

Phase 3: Launch

We expect to launch Stepping Out in summer 2008. The formal evaluation of the programme will continue as the programme expands and will provide the basis for published research.

Ultimately we plan to extend the work we are doing in stroke to related chronic diseases.

Web site goes live



The Stepping Out website has now been published. The site is in its infancy and will be improved and updated constantly.

Visit www.steppingoutuk.org.uk for all the latest developments and news.

In addition, this quarterly newsletter is being distributed at conferences and workshops and, via email, to interested professionals, charities and patient groups.

We have now created a database of professionals across the UK who are very keen to be kept in touch with latest developments in Stepping Out.

www.steppingoutuk.org.uk



This programme encourages self-management, focusses on the successes, and decreases dependence on therapists.

What's new?



Mechanisms of Engaging Patients in Self Care and the Sociocultural Implications. In July 2007 the Royal Holloway University hosted the second ESRC supported symposium. A selection of articles will be published in a special issue of **Health Sociology Review**.

Key self-management discussions focussed on:

- the increase in chronic disability and illness
- how the majority of individuals desire to take an active role in their treatments
- the most effective form of interventions
- How to empower individuals to take more control *and* change clinical outcomes
- which groups are excluded from current self-management programmes
- which individuals currently tend to participate in existing programmes
- self-management replacing some treatments and providing an implied fiscal benefit
- self-efficacy as a mediator of change
- the long term benefits of self-management
- disease specific interventions versus generic self-management programmes.



Supporting Self Care in Primary Care by Ruth Chambers is an excellent book on self-care published by Radcliffe. All healthcare professionals involved in primary care will find this practical guide invaluable, as will healthcare managers and health promotion specialists.

Published last year the book may be obtained via the publisher's website at www.radcliffe-oxford.com



Dr Sally Lindsay at the University of Salford coordinates the UK chronic disease self-management research network. Email Dr Sally Lindsay (s.lindsay@salford.ac.uk) if you would like to receive regular updates on recently published papers and upcoming conferences.

The Stepping Out team

The Stepping Out team is based at:

Faculty of Health and Social Care Science,
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The Advisory Group

Dr Fiona Jones Project leader
Dr Ajay Bhalla Consultant Stroke Physician
Eileen Collins Stroke survivor
Dr Helen Hosker GPwSI Older People Service
 Development and Intermediate Care
Steve Parker Design Consultant
Dr Cecily Partridge Reader in Physiotherapy
Maggie Pettifer Publishing Advisor
Carole Pound Director of Innovation, UK Connect
Jane Williams Stroke Nurse Consultant

The advisory group meets twice a year.
The next meeting is scheduled for November 2007.

Register your interest

If you would like to join our mailing list and receive regular updates on the progress of Stepping Out and a copy of future editions of Stride, please forward your contact details to Kirsty Martin at:

stepout@hscs.sgul.ac.uk

Acknowledgement

Stepping Out is indebted to each of its 10 original contributors. Their willingness to share their experiences, their efforts and their perseverance have been an inspiration to us all.