

stride

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For everyone concerned with stroke rehabilitation

Stepping Out: a case study

Brian had a stroke on Christmas Day. He was 56 years old.

Brian, a printer, had been in good health and fine up until the day of his stroke. He collapsed while getting out of bed in the early hours of the morning. He felt the right side of his body just completely give way.

Luckily, his partner Jan realised immediately that he had had a stroke, and called an ambulance. Brian spent the next few weeks in hospital.

One of the first things Brian remembers doing in hospital was to set himself a target for going home. When he arrived onto the stroke unit, on 31 December, he knew he was in for a long haul, so he decided he wanted to be out of hospital by his next birthday, 22 February. Actually he managed it a week early.

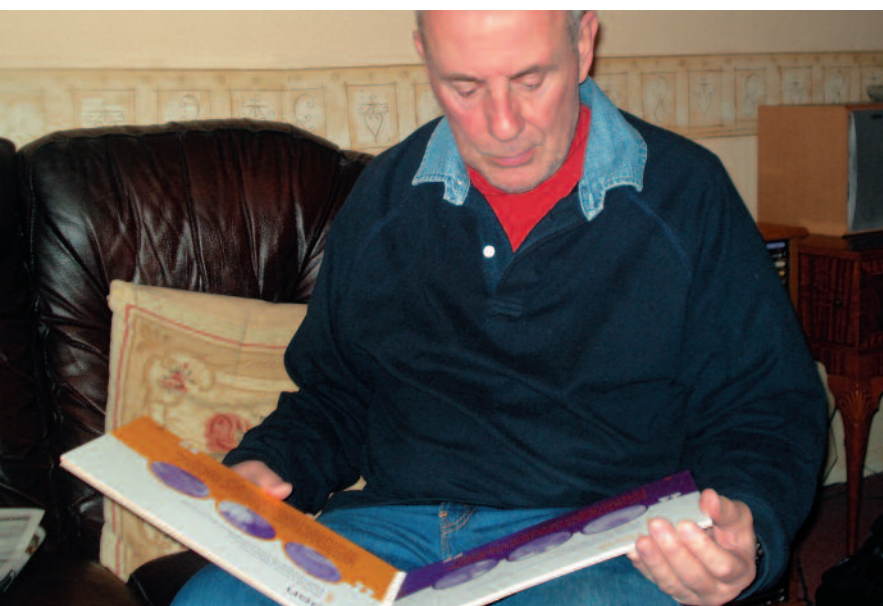
Despite achieving his target, Brian initially felt frustrated that he could do very little for himself when he got home. He had minimal movement in his right arm, made worse by swelling and pain, and he was unable to walk without difficulty. However, within a week, he could

manage with help to climb a flight of stairs, although progress with his arm was much less. He concentrated his efforts on daily exercises and remembers that during this period he had to learn to manage left-handed.

Brian used the Stepping Out Workbook to set further targets and to record his progress. He says, 'Odd things like doing up your belt and buttoning your shirt were difficult, all the small things that involve getting the hand and arm working right. Obviously it took time because I didn't have a lot of function there'.

Brian also used the Workbook as a guide to measure how he was doing. 'If you continue to refer to the Workbook then you can't go wrong really. There might be a day where you think "Well I did it yesterday so I should be able to go a bit further with it today".'

'It doesn't always happen like that, but gradually you start to see an improvement if you keep repeating everything, so long as you don't go crazy at it and try to get everything done in a day because it doesn't work that way.'



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steppingout

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



Update from the pilot sites

In January and February 2007, **Stepping Out** training workshops were held at three different pilot sites (Inverness, Christchurch, and South London). 45 practitioners working at all stages of the stroke journey attended, and the Stepping Out approach to stroke self-management was introduced along with the Stepping Out workbook.

Focus groups were held a few months later in May and June, to gain feedback from the sites about the acceptability of the workbook, and whether the training was effective in being able to prepare practitioners for the skills required to deliver the Stepping Out stroke self-management programme.

We have now reviewed the comments from each of the pilot sites, and used the feedback to modify our workbook and training.

Changes to the workbook will include:

- Some additional stories from stroke survivors who have developed effective and innovative self-

management strategies, which have helped them continue to make progress after their stroke.

- There will be some changes to the layout, colour scheme and readability following feedback given by Connect.
- Some reorganisation of the target setting section to include a section for recording short term targets as well as long term goals.
- We will also include worked examples of targets and goals from stroke survivors.

All these changes will improve the clarity and usefulness of the workbook and make it more accessible.

We are very grateful to all the practitioners, stroke survivors and carers who have given us this constructive feedback. The new workbook will be unveiled on our stand at the UK Stroke Forum in December 2007.

We look forward to meeting you all there.

Dr Cecily Partridge, Emeritus Reader in Physiotherapy, University of London says:

At a time when the words 'person centred' and 'patient centred' are frequently on our lips and in our journals, the Stepping Out programme is so refreshing in that it really does put the patient at the centre of their own management, enhancing their confidence and ability to recover skills lost through their stroke in a personalised way.

The Workbook is not based on any particular treatment approach, and can therefore be added into any programme. It could help to bridge the difficult gap between hospital and reliance on others and the return home.

Clearly, there is a lot more work to be done but it should be possible at the end of the evaluation process to be able to identify those people for whom the workbook will be most effective and the optimum times for its use.

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



Looking ahead

Come to our stand at the ideas fair at the UK Stroke forum 4-6 December 2007. There will be a Stepping Out presentation, and the revised version of the Stepping Out workbook will be available to view.

We are taking bookings for Stepping Out workshops in 2008. Although numbers are limited for the first part of 2008 while we recruit and develop new trainers, please email us at stepout@hscs.sgul.ac.uk, or contact us through our website, if you are interested.

We are very happy to chat with you about how the workshop could be adapted to meet the needs of your particular stroke service, whether in an acute or community setting.

We are currently making applications for further grants to support the development of a new carers resources pack which will accompany the workbook, and to fund the production of the first few thousand copies of the Stepping Out workbook.

Stepping Out will eventually become an independent

charity, but at present it will remain a dedicated project run from the Faculty of Health and Social Care at St George's University of London led by Dr Fiona Jones, Principal Lecturer in Physiotherapy, under the aegis of the St George's Hospital Charity (no. 241527).

The National Advisory Group for Stepping Out is multi-professional and includes stroke survivors and carers, along with experts in many aspects of stroke care.

A further feasibility study of Stepping Out is due to start in 2008 in Belfast, Northern Ireland. We are working together with Dr Sheila Lennon, from the University of Ulster, to define our intervention, refine the specific outcomes and test the feasibility in a pilot RCT.

More information about the feasibility study will be available in our next newsletter.

A number of consultation events have already taken place with community stroke teams, and we are currently training a small group of practitioners to be able to deliver the Stepping Out programme.

Stepping Out Workshops for practitioners 2008

We aim to deliver a minimum of 12 Stepping Out Workshops to practitioners across the UK in 2008.

Workshop participants will receive a comprehensive resource pack containing a thorough critique and summary of both the relevant research on self-management and self-efficacy, and of all current evidence in relation to stroke. In addition, participants will receive a copy of the Stepping Out Workbook.

During each workshop there will be discussion on the research and theoretical basis to self-efficacy and self-management. Participants will be introduced to the Workbook and will be able to practise target setting skills and review more worked examples from previous participants in the Stepping Out programme.

The Workshops will also include discussion and debate on questions raised by previously trained practitioners.

Although the Workshops follow a similar format, there is infinite scope for adapting the content to address local needs. Training can be directed to any stage of the stroke pathway in which practitioners are engaged (acute, early supported discharge, community).

Come and view an example of the Stepping Out Workshop Programme at the Ideas Fair, UK Stroke Forum Conference on 4 - 6 December 2007 Harrogate International Centre.



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

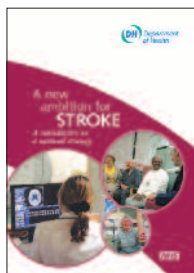
What's new?

Self-management research for individuals with long-term conditions is moving at a pace, and there are a number of reviews which provide a useful critique of the different approaches and interventions.

Currently there is limited evidence to identify the best approach – whether it be group versus individual, lay versus professional-led, generic versus disease-specific interventions. The best approach for stroke survivors is also unknown, although it is likely that a range of different interventions are necessary given the complexities of impairments and activity limitations experienced by individuals post stroke.

In the consultation document produced by the Department of Health stroke working party, **A new ambition for stroke**, there is a clear acknowledgement that more effort is required to help individuals cope effectively with the transition between hospital care, rehabilitation and reintegration back into the community. There is also recognition that support to regain well-being does not have to be provided by rehabilitation professionals, and could be provided through a wide range of self-management activities and self-care groups (DH/Vascular Programme 2007, A new ambition for stroke; Chapter 2. 21&22. p32).

Useful publications:



A new ambition for stroke. A consultation on a national strategy. Department of Health. DH/Vascular Programme/Stroke (2007).

Chronic illness, expert patients and care transition. *Sociology of Health and Illness*, 29(2), 27-45. D Taylor & M Bury (2007).

A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness. M Bury, J Newbould & D Taylor (2005).

Self-management interventions for chronic illness. *Lancet*, 364(9444), 1523-1537. S Newman, L Steed, & K Mulligan (2004).

The Stepping Out team

The Stepping Out team is based at:

Faculty of Health and Social Care Sciences,
Grosvenor Wing,
St George's University of London,
Cranmer Terrace,
London SW17 0RE

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
Dr Jane Williams Stroke Nurse Consultant

The advisory group meets twice a year.
The next meeting is scheduled for Spring 2008.

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 the team 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.