



Stroke Support Groups

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Stroke Objectives

Objective:

To eliminate preventable death, disability and suffering from stroke; and to help survivors live the best life possible.

Key strategy Points on Stroke:

- Advocate for better services and policies
- Deliver world class information and awareness campaigns
- Provide access to community-based support for all stroke survivors nationally by 2020.



Our Challenge

Advocacy: Stroke traditionally low priority in national policy.

Awareness: No State support for awareness and information campaigns that save lives and cut health costs.

Support: CVD is the number 1 killer disease and cause of acquired disability. But community services inadequate countrywide. IHF 94% funded by public donation and cannot address this alone.



Progress to date

Since 2011 we have played a key role in many successes:

- Reduction in stroke deaths by 26% and in the rate of direct discharge to nursing homes by almost half.
- An increase in population-wide FAST awareness from 30% to 89% - the highest recorded national rate in the world.



The case for stroke support

Irish and overseas research provides strong evidence of the role of stroke support in recovery. Irish survivors spoke of a lack of understanding of invisible symptoms even among family and friends.

"In contrast, respondents mostly spoke about a sense of belonging when they described involvement with a stroke support group. They reported many benefits of the groups including increasing self confidence, social interaction and being a link for help."

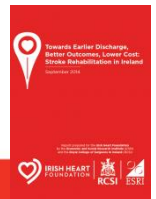


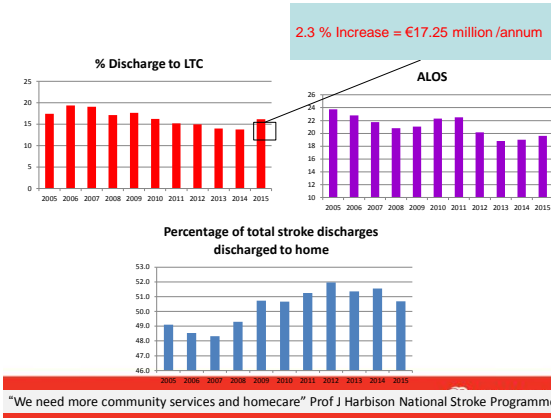
Cost effectiveness

ESRI research shows that out of a total annual direct cost of stroke to the State of up to €557m, as much as €414m is spent on long-term care and less than €7m on community rehabilitation and support.

The architect of the HSE's National Stroke Programme, Prof Joe Harbison said of stroke support:

"It is an easy and inexpensive way of improving quality of life for hundreds of stroke survivors and may even help to keep them in their own homes and out of long term care."





Stroke

8000 hospitalised strokes in Ireland each year. At least 60,000 stroke survivors.

Younger stroke

Surge in working age stroke identified in National Stroke Audit.

We have set up a Life After Stroke Facebook group; held a national launch in Croke Park; will hold regional meetings in 2018, including for Donegal/Sligo/Leitrim and Cavan/Monaghan/Louth in 2018.

Where demand is sufficient, we will initiate volunteer led support groups. We are particularly keen to serve people in rural areas.



IHF stroke support groups

There are 18 groups in the IHF network so far, including three in the CHO1 area: Cavan, Monaghan and Sligo. We will establish groups in Donegal and Leitrim when sustainability KPIs are met.

	Cavan	Monaghan	Sligo
Members	17	19	45
Ave weekly attendance	12	12	28



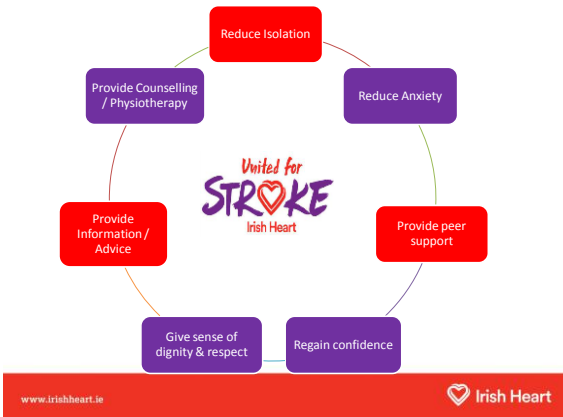
How our support groups work

One Hour of Social Therapy

Group discussions, Activities, Games, Outings/Trips, Information and Guest speakers

Goals/Objectives:

- > Bring people together who want to meet others on a similar stroke journey to themselves.
- > Provide a forum for stroke survivors to share experiences, reduce isolation and anxiety.
- > Provide and grow a social network for stroke survivors to regain confidence.
- > Assist members in any way we can, to live with dignity, respect and participate fully in community life.
- > Provide people with information and services such as group physio, counselling and advice.
- > Enable survivors to give and receive encouragement to meet personal recovery goals and maximise quality of life.
- > Promote good health and well being through daily access to both general information and personal advice, from trained nurses on our National Heart and Stroke Helpline and access to local care professionals.

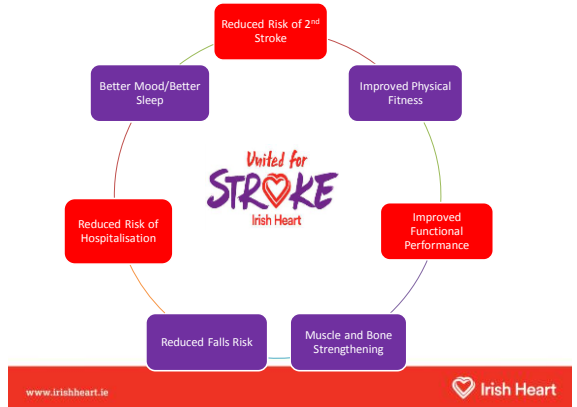


One Hour of Group based exercise programme:

Aerobic Exercise , Strengthening Exercises, Flexibility Exercises, Neuromuscular Exercises

Goals/Objectives:

- Increase walking speed/efficiency/ endurance/co-ordination
- Increase muscle strength and endurance, improve cardiac demands
- Increase Movement, Prevent stiffness, reduce risk of injury, improve performance
- Improve balance, quality of life, reduce falls, reduce fear falling, improve safety



Feedback Stats for Sligo, Cavan & Monaghan

Sr	Evaluation Sheet Data Sligo/Cavan/Monaghan					
		Poor				Excellent
		1	2	3	4	5
1	How do you rate the location of group?	0	0	7	12	28
2	How would you rate the group?	0	1	4	15	27
3	How would you rate the facilities in your group?	0	0	3	16	28
4	How would you rate the importance of group exercises?	0	0	0	8	39
5	Since starting the exercise programme do you feel you have benefited from the group sessions?	0	0	3	16	28
6	How do you rate the importance of peer support?	0	0	2	10	35
7	How do you rate the social element of the group?	0	0	1	10	36
8	How do you rate supports from the Irish Heart Foundation?	2	1	2	21	21
9	How do you rate guest speakers/information for the group?	0	1	1	18	27
10	How do you rate our stroke support group coordinator?	0	0	2	3	42
11	How would you rate the Stroke Support?	0	2	0	19	26
TOTAL		2	5	25	148	337

Key performance indicators

Year 1	Cav	Mon	Sligo		Cav	Mon	Sligo
Service users				Evaluation			
Total members year end	10	10	20	Service user satisfaction	80%	80%	80%
Average attendance	8	8	16	Stakeholder survey			
New members (post launch)	5	5	5	Benefits of exercise/physio	✓	✓	✓
Awareness of policies (ie complaints)	75%	75%	75%	Research into evaluation methods overseas	✓	✓	✓
Nos using Helpline receiving IHF info	8	8	15	Coordinators			
Activity				No of home visits	7	7	10
Min number of meetings	44	44	44	Coordinator meetings and teleconferences	6	6	6
% for exercise/ group physio	100	100	100	Training (year 1 CPR, manual handling, computers)	All	All	All
Numbers s receiving counselling	5	5	5				

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Year 1	Cav	Mon	Sligo	Year 1	Cav	Mon	Sligo
Promotion of groups				Stakeholders			
Spokespeople	3	3	5	Meetings with stroke unit team	3	3	3
Posters distributed				Meet HSE execs re cooperation	✓	✓	✓
Community meetings/talks	3	3	3	Meet community partners	3	3	3
Media appearances local papers/radio	5	5	5	Sustainability			
Younger support network				Fundraising target	3k	3k	5k
Stroke survivors attending national meeting	5	5	5	Assessment of costs and income			
Promotion in local media				Assessment of future costs and income			
Commitment to regional meeting	✓	✓	✓				
Commitment to local Facebook groups	✓	✓	✓				

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Community stroke hub

Our intention is that our support groups and Helpline will be the cornerstone of broader community stroke hubs which also deliver the following:

- Stroke recovery/family liaison service
- Working age support and social groups
- One-to-one peer support service in hospitals
- Self management programmes
- Back to work support
- Child and teenage stroke survivor support service

100% of funds raised in a local area will be spent there and surpluses will be invested in these programmes.

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Referral pathway

The HSE's National Stroke Programme has agreed to hardwire the support network into its stroke care pathway so patients are routinely referred to their local support group at discharge. This will underpin our close cooperation with hospital stroke teams in setting up and running our Groups.

These links ensure that discharged stroke survivors are informed of the benefits of joining a group. On receipt of a referral, a home visit is arranged to assess the ability of each person to attend .



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The cost of stroke support

These costs do not include head office costs for management, admin etc. Costs incurred by our Helpline services, PR, information materials and the occasional financial support we give to members are also not included.

Coordinator's wages – Each coordinator works 10 hours a week for each group they run. Current wage rates are set at €15 per hour for all coordinators.

Hire of premises - for weekly meetings

Group physio/structured exercise - instructors for weekly sessions

Counselling - when required by participants

Equipment - including coordinator's phone and laptop; and equipment for clubs such as bocchia sets, games, quizzes, board games, art materials etc

Transport – to meetings in special cases and for group outings.

Training - Coordinators and volunteers receive regular compulsory and optional training as appropriate at IHF head office

Cost of co-ordinator's travel - to home visits of new members, company training, meetings with hospital stroke teams and other meetings to promote the groups.

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Testimonials

"The support group acts as a peer group for those who require it as they are a vulnerable group who find it difficult to come to terms with their deficits and emotional liability. Peer support cannot be underestimated as it provides a forum for survivors to meet and talk to others who are effected by this disabling illness. Physical exercises are part of the support group's objective which I believe is beneficial to all. Speakers from multidisciplinary groups attend the group as well as other agencies e.g. Healthy Eating, respite, financial organisations. All of these are extremely beneficial and the support group acts as a one stop shop"
Mary Durkin, Nurse SUH & Stroke Survivor Relative

"This is an area where a Stroke Support Service can be of immense assistance. Since my discharge in 2003 I have been involved in a local organisation here in Sligo. During this period I have met many Stroke survivors. We had a very focussed vision for our members over the years. It was quite evident, that whilst there was nearly always a continuing need for medical assistance, the emphasise was also very much on the mutual support we could offer each other in many other areas. In particular, the assistance we could offer each other in sharing our feelings and information with like minded people, thru meetings, activities and outings. It was put to me many years ago, that a Stroke Support group was the Social Rehabilitation side of recovery. I firmly believe this and would greatly advocate further expansion of such services across the country, along the professional model as being promoted and in place by the IHF."
Edward Blake Stroke Survivor Sligo

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