**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.”
"We need more community services and homecare" Prof J Harbison National Stroke Programme.

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.

<table>
<thead>
<tr>
<th></th>
<th>Cavan</th>
<th>Monaghan</th>
<th>Sligo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members</td>
<td>17</td>
<td>19</td>
<td>45</td>
</tr>
<tr>
<td>Ave weekly attendance</td>
<td>12</td>
<td>12</td>
<td>28</td>
</tr>
</tbody>
</table>

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 wellbeing 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

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**Feedback Stats for Sligo, Cavan & Monaghan**

<table>
<thead>
<tr>
<th>Indicator: Stroke Support Sligo, Cavan, Monaghan</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you rate the location of group?</td>
<td>0</td>
<td>4</td>
<td>12</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>How would you rate the group?</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How would you rate the facilities of your group?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How would you rate the importance of group exercises?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
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<tr>
<td>How do you rate the social element of the group?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
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<tr>
<td>How do you rate peer support?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How do you rate the Stroke Support?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How do you rate the support from the Irish Heart Foundation?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How do you rate guest speakers/information for the group?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How do you rate our stroke support group coordinator?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>How do you rate our stroke support?</td>
<td>0</td>
<td>12</td>
<td>6</td>
<td>13</td>
<td>22</td>
</tr>
</tbody>
</table>

**TOTAL:** 2 5 25 150 337
Key performance indicators

<table>
<thead>
<tr>
<th>Year 1</th>
<th>Cav</th>
<th>Mon</th>
<th>Sligo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service users</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total members year end</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Service user satisfaction</td>
<td>90%</td>
<td>80%</td>
<td>90%</td>
</tr>
<tr>
<td>Average attendance</td>
<td>8</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>New members (post launch)</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Awareness of policies (ie complaints)</td>
<td>75%</td>
<td>75%</td>
<td>75%</td>
</tr>
<tr>
<td>Nos using Helpline receiving IHF info</td>
<td>8</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Advice</td>
<td>80%</td>
<td>80%</td>
<td>80%</td>
</tr>
<tr>
<td>Min number of meetings</td>
<td>44</td>
<td>44</td>
<td>44</td>
</tr>
<tr>
<td>% for exercise/group physio</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Numbers receiving counselling</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Cost of stroke support

These costs do not include head office costs for management, admin etc. Costs included 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 bocce 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.

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.

The cost of stroke support

The HSE’s National Stroke Programme has agreed to hardware 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.

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 affected by this disabling illness. Physical exercises are part of the support group’s objective which is also beneficial to all. Attendees 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 focused vision for our members over the years. It was quite evident, that whilst there was nearly always a continuing need for medical assistance, the emphasis 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 the minded people, help 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 HSE."—Edward Blake Stroke Survivor Sligo

Referral pathway

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.
The stroke support group welcomes each and every one and provides the opportunities to learn in their own personal way. In a safe and respectful environment, which is deeply appreciated by all attending. The variety of differences enhances the chance of everyone finding something to improve their quality of life during each and every session. As there are endless variations of individuals journeying through life, there are endless possibilities and options to be discovered and embodied. The trusting environment created by all attending creates confidence to share and empower each other.

The stroke support group in Cavan was established in June 2016 and has grown steadily it is seen as an integral part of recovery. We welcome all to come to the group weekly or as they can. We have been fortunate to have the support of the Irish Heart Foundation to support and maintain the group, with a wonderful facilitator to oversee the group in Cavan.

Frances Smith CNS Stroke Care, Cavan General Hospital

I have been involved with Julie in setting up the Weekly Stroke Groups in Cavan and Monaghan. There are currently few community services in place for clients when they have had a stroke and are finished with therapy intervention. There is little ongoing opportunity for exercising the body and the mind. This weekly group fills this gap and feedback from clients attending the group have been really positive.

Allied Health Professional staff are delighted to inform clients regarding this weekly group as a way to progress them through their journey with stroke. The initiative of setting up these groups by the Irish Heart Foundation is extremely positive at a time when we have many older and young people surviving stroke.

Fiona Gilliland MISCP, Physiotherapy Manager 1, Cavan/Monaghan Physiotherapy Department, Primary Care Rosnakey, Monaghan