

Heart Disease & Stroke Cross Party Group
Wednesday 16th September 2015,
Committee Room 5, 1800-2000

Advocacy for people affected by heart disease and stroke

1. Welcome & Apologies

MSP Attendance
Dennis Robertson
Dave Thompson
Joan McAlpine

MSP Apologies
Richard Simpson
Nanette Milne
Claudia Beamish
Anne McTaggart
Jim Hume

2. Matters arising

2.1 Minutes from previous meeting of 26th May & 10th June 2015

Proposed by Chris McNamee ; Seconded by Mark O'Donnell

2.2 Update on MSP membership of the Cross Party Group

Dennis Robertson updated the group on the new MSP membership and co-conveners. Margaret McCulloch has step down as co-convenor of the CPG but Anne McTaggart (Labour), Nanette Milne (Conservative) & Jim Hume (Lib Dem) have all joined as co-conveners

3. Presentations

3.1 **Shirley and Steven Todd;** Young stroke survivor and husband

Shirley shared her experience as a stroke survivor with group. Her presentation was very detailed and emotive and allowed the group to understand the range of advocacy needs required for patients following a stroke. Her husband Steven told the story from the family/carer side and the challenges faced when a family finds themselves in such a situation. Their story was a very powerful example of where advocacy and advice can better support not only patients but families in accessing services and rights as stroke patients

4.2 **Muriel Mowat;** Operations Manager at Scottish Independent Advocacy Alliance

Muriel discussed the work of the Alliance and shared useful resources that the public and health care professionals can access. Muriel highlighted resource constraints as one issue for creating delays in service provision to stroke survivors.

4.3 Tim Bone; Fairway Advocacy

Tim Bone shared the story of Fairway Advocacy and shared example cases that had been taken on behalf of stroke survivors. More about Fairway Advocacy can be found on their website <http://www.fairwayadvocacy.org.uk/>

4. Discussion

Following the three presentations the Chair invited comments and questions from the Group. There were a wide range of questions for the panel some of the themes have been highlighted below;

- **How can advocacy support people to live a “normal” life:** This was an important issue about supporting survivors to return to life as normal as best and quickly as they could and not treating them differently
- **Accessing Advocacy from Day one:** The experience of Shirley and Steven showed that accessing advocacy from the start is vitally important. Delays in access only limits a survivors ability to move forward and develop independently again
- **Carers Allowance:** There was an in depth discussion regarding Carers Allowance and how carers can be better supported when circumstances change so rapidly
- **Advocacy Information:** Both The Stroke Association and CHSS highlighted advocacy advice and information on their respective websites for patients, carers and professionals to access.

5. AOCB

Parliamentary Question from carers and advocacy organisations about the National Guidelines for Carer Advocacy – It was agreed the ramifications of this PQ to be discussed at next Carers CPG.

Update for Stroke Charter Subgroup – A survey is currently being prepared by the subgroup to find out how the charter has been used and what has been done with it. There is a proposed further meeting to discuss how the charter has influenced the Stroke Improvement Plan. Update given by Angie McLeod of The Stroke Association,

James Cant, Director for Scotland, BHF Scotland – James Cant attended his first CPG in capacity as Director for BHF Scotland and thanked the group for their welcome and that he looked forward to working closely with the group and partners around the table in the near future.

7. Dates for meetings in 2015:

- Wednesday 9th Dec 2015 – Out of Hospital Cardiac Arrest in Scotland