

## **FAIRWAY ADVOCACY LAUNCH**

### **“Independent Advocacy for Neurological Conditions: Forming Partnerships”**

The launch of Fairway Advocacy took place at the Robertson Trust, Robertson House, Bath Street, Glasgow on Thursday the 25<sup>th</sup> of September 2014. Thirty two delegates attended, representing a range of neurological charities, West of Scotland Advocacy Services, Scottish Independent Advocacy Alliance, Health and Social Care Alliance, Glasgow Disability Alliance, Health Boards and service users. The common neurological conditions such as stroke, Parkinson’s disease, M.E. and Multiple Sclerosis were represented, as well as less common conditions such as Progressive Supra-Nuclear Palsy and Tourette’s syndrome. (See Appendix for a complete list of registered organisations)

PowerPoint presentations to accompany talks will be available at [www.fairwayadvocacy.org.uk](http://www.fairwayadvocacy.org.uk)

#### **“Welcome”.**

##### **Maida Gibson (Chair Fairway Advocacy)**

Maida Gibson, Chair of Fairway Advocacy, opened the meeting by welcoming delegates. She started by thanking the Robertson Trust for providing the facilities for today’s meeting as well as the financial support given through grant funding. She passed on Fairway Advocacy’s gratitude to the Robertson Trust Trustees. Maida also thanked Awards For All, who had also provided support for this first critical year for the Fairway Advocacy Project. Maida pointed out that the catering had been provided by us as an example of making the best possible use of funds available.

Maida said that the start of any project is always difficult and frightening, but that Fairway had done a huge amount of research into the need for an Advocacy Service for people with neurological conditions, indicating that the types of conditions and the evidence obtained would be presented during the course of the meeting. She outlined the contents of the delegate’s pack containing in particular, the Fairway flyer with contact details, a recent publication from Fairway in Open Door, a publication of the Scottish Disability Equality Forum, as well as our recent Viewpoint article that was available on both the Alliance and the Scottish Independent Advocacy Alliance websites. She commented that the research that had been done demonstrated that there was a considerable need for advocacy within this client group, and that at the moment they found Independent Advocacy

difficult to access under current legislation. She outlined the difficulties of people with long-term conditions confronted in the current climate of bureaucracy, combined with the decreased staffing in government departments tasked to ensure that benefits and grants are properly used. She stated that there was a huge need for independent advocacy for clients who for various reasons were unable to speak for themselves.

Maida went on to outline the day's programme and hoped that there would be participation in the round table discussion that would give ample scope to explore any of the issues important to the delegates. She outlined the subsequent question and answer session and her own summing up at the end of the meeting. She then passed the meeting over to Ian Bone, to outline the purposes of Fairway Advocacy in terms of whom, how and why.

## **TALK 1**

### **“Who are Fairway Advocacy and what are our aims” & “Why do we believe there is a need for advocacy for those with neurological conditions”?**

#### **Ian Bone (Trustee Fairway Advocacy)**

Ian started off by outlining who Fairway Advocacy was and what were their aims. He described the history of the organisation established back in May 2013, achieving charitable status in September of that year. He described the backgrounds of the current trustees coming from those of healthcare, work within the charitable field, accountancy, governance and social care.

He outlined Fairway's four main aims, firstly to establish an independent advocacy pilot service for those with neurological conditions in West Central Scotland. Next, to develop links and partnerships with the Neurological Charities, Advocacy Services, Health Professionals, Scottish Independent Advocacy Alliance, Neurological Alliance, Scotland. Health and Social Care Alliance and the Disability Alliances such as the Glasgow Disability Alliance, represented here today. He next stressed the importance of collecting and disseminating evidence of need through surveys and information sharing, and finally the commitment to lobby, in partnership with many here today, for widening statutory access to independent advocacy.

He next went on to outline neurological conditions in terms of their definition and individual prevalence and incidence within Scotland. He pointed out that Health and Social Care, Neurological Alliance Self-Management report had stated that these conditions accounted for a high proportion of severe and progressive long-term disability within our population.

He then went on to outline why Fairway had focussed on these conditions, indicating that this was where our personal and professional expertise lay, that the conditions themselves were often the subject of more misunderstanding, mis-information and discrimination than any other group with long-term conditions. The disability was often unseen, such as in epilepsy, and that the division between the brain and the mind was in any case an artificial one, given that people with conditions affecting the mind had statutory access, but those with conditions of the brain did not.

He next went on to outline the Independent Advocacy Guide For Commissioners, Scottish Government, December 2013, again emphasising the comment in the introduction from the Cabinet Secretary for Health and Wellbeing, that advocacy should be available to anyone who needs it, whilst on the other hand the Guide For Commissioners clearly laid emphasis on the statutory responsibilities under the Mental Health Care and Treatment, Scotland Act 2003. He next went on to describe the perceived need for advocacy for long-term physical conditions such as those affecting the brain and spinal cord. He drew attention to the S.I.A.A. Map of Advocacy across Scotland, 2011-2012, the NHS Scotland Charter for People Living with Stroke in Scotland 2014 and the Headway Glasgow Directory of Brain Injury Services 2013, each of these supporting the need for advocacy for long-term physical and neurological conditions.

He next discussed evidence collected from two surveys conducted by Fairway, of service users and neurological alliance members, proposed future surveys and the need to collect information on the unmet need for those with neurological conditions from other advocacy services. Finally he outlined the recent Health Board Survey conducted by Fairway under the Freedom of Information Act. In particular, he drew attention to the various health board advocacy plans quoting from these the recognition that physical and neurological conditions required advocacy, but that there was currently a significant gap within the service for such persons.

He mentioned the various advocacy services that do see a small volume of patients with stroke, acquired brain injury and other neurological long-term conditions. He stressed given the incidence and prevalence of these conditions within our community, currently only a very small volume of such persons were seen by advocacy services and then only after those with statutory access under the Mental Health Act, had had priority.

He concluded that Fairway were offering a service which he perceived as being needed, not consistently provided, associated with confusion surrounding statutory access and requiring a pilot service such as the one proposed by Fairway, that would act as an exemplar for future such services.

He again emphasised that under current legislation, the statutory right to access may be “championing” over need.

## **Discussion:**

There was a brief break for questions and the delegate from one of the three local advocacy services commented that there was a gap in the service, but that they had recently had extended their services to those with physical disability. The delegate drew attention to the Joint Services Plan and commented that in Glasgow there were approximately one hundred thousand individuals living with physical disability and that whilst their advocacy project had extended, access to such individuals with recent legislation was putting more pressure for those with physical disability to be seen. The advocacy delegate welcomed the Fairway Advocacy Project noting that it was a highly specialised “niche” service and what offer some relief on the pressure placed upon other advocacy services to try and accommodate such service-users.

The meeting was informed that the Scottish Independent Advocacy Alliance was about to publish an up to date map of advocacy services. In real terms there had been a cut in funding associated with an increased number of advocacy service users, also now with the pinch in resources, the advocacy services were not only being required to prioritise those with mental health disorders, but also people who were subject to compulsion under the Mental Health Act. It was pointed out that even the statutory duties in some areas were currently not being met. It was pointed out that on the whole, all over Scotland, access if anything was shrinking and that there was no service comparable to the one Fairway Advocacy was offering anywhere else in Scotland.

Another delegate from another West of Scotland Advocacy Services pointed out that some years ago he had been asked if offered a bit of extra funding, how that would be used. The delegate had then said he would use it for physical disability. He pointed out that his organisation still takes on persons with physical disability, but compared with mental health the numbers were small and the budget for such a service was getting tighter and tighter and thus it was impossible to manage increasing demand.

One service user with a neurological disability pointed out that she had tried to obtain independent advocacy services, but had been unsuccessful. A further advocacy service delegate pointed out that it was becoming increasingly difficult to provide services for those who did not have statutory access,

and that there was a reluctance to turn anyone away if there was evident need. He said that he hated to think that an advocacy service might be in the position of saying to an individual that they did not fulfil the criteria and therefore could not be seen and helped.

It was also pointed out that neurological conditions in time are often associated with the development of a mental health problem, this sometimes being situational and a reflection of the stress in coping with issues that persons with these conditions had been subject to. It seemed ironic that then they could access services under the Mental Health Act, but they required to develop secondary mental health issues on top of their initial neurological problem before this allowed them statutory right of access.

Maida Gibson introduced Tim Bone, who was going to outline service users to date, their issues and outcomes as well as future plans for the service.

## **TALK 2**

### **“How we can deliver a service? A review of current casework and future plans”**

#### **Tim Bone (Advocacy worker: Fairway Advocacy)**

Tim initially addressed case-load and cases with respect to current experience. He outlined that our service had started in late April 2014, that currently on the basis of available funding, approximately eleven hours per week was available for independent advocacy, and that to date there have been nine clients, referrals coming from organisations such as Action for M.E., The Brain Tumour Charity, Revive, Headway and Ceartas. He outlined that four clients were still currently active, that in terms of issues dealt with, there had been thirteen resolutions and given the number of hours of work per week and the duration of the project this would if scaled up, amount to a hundred and forty resolutions per year.

He next described five anonymised cases. The first, a referral from Headway, had been someone involved in a road traffic accident, sustaining a head injury. There had been a diagnostic conflict as to whether head injury or post-traumatic stress disorder was the correct diagnosis and without formal investigations in terms of brain imaging, neuropsychological assessments, a psychiatrist had eventually diagnosed post-traumatic stress disorder and the client had been faced as a consequence

of this, with many problems in terms of the misinterpretation of his behavioural difficulties. As a consequence his general practitioner, who the client had seen on many occasions, would not refer for another opinion. Following support and guidance by the independent advocate, the client was eventually seen by a neurologist who suspected diffuse head injury and had referred for MRI in order to clarify the diagnosis. The client was now pleased that his issues were being thoroughly and appropriately investigated.

The second client had been referred by the Brain Tumour Charity; adaptations were planned for his home but had been cancelled by occupational therapy. The client was now facing the prospect of having to move house. With the support of the independent advocate, occupational therapy was contacted and the client was presented with several new plans for his accommodation, the first being identical to the one that he initially had favoured. The client selected this and the local authority committed to providing these adaptations. As a consequence the client's issues were settled in that his home was now going to be appropriately adapted and the need to move no longer an issue.

The third client was referred by Action for M.E., having had fifteen years of symptoms suggestive of M.E.; she had attended her General Practitioner over many occasions and the doctor had refused to recognise as these being symptoms of anything other than a psychological illness. The client contacted the Independent Advocate. The Independent Advocate went through the N.I.C.E. guidelines with the client and prepared an account of her symptoms in conjunction with her, to be presented to the general practitioner. The General Practitioner took cognisance of the N.I.C.E. guidelines in the context of the client's ongoing symptoms. The General Practitioner now gave a diagnosis of M.E., provided some medication to help with her depression and arranged for her to be referred to an M.E. Support Group. The client was delighted that after several years of unsatisfactory consultations with little progress, a diagnosis had been made and she had been referred for support and understanding of her condition.

The fourth client was also referred by the Brain Tumour Charity. The individual had worked in healthcare in a nursing capacity, and had been deemed no longer fit for this and had been placed in a medical records department, carrying out repetitive simple tasks whilst undergoing regular M.R. imaging to monitor the progress of his condition. Imaging had been inconclusive, a year had almost passed in which his employers were required to find him an alternative post and review appointments with Occupational Health were being cancelled, meaning that the individual was almost reaching the end of the year in which his employers were obliged to find alternative employment. The client contacted Fairway in month eleven, as a result of helping him represent his case the one year commitment had been extended. He had been allocated a redeployment officer

and was having fortnightly assessment meetings. The client was satisfied now that attempts were being made to find work for him that was appropriate to his abilities, and that he was no longer in a situation where his employment could have been terminated.

The final client was a self-referral, having seen a flyer on Fairway Advocacy in his local library. He has Parkinson's disease. His care-plan was outdated. He had complained to his care provider about this, but things had not moved on. He had been complaining about this for over one year. With the support of his independent advocate, his care provider was contacted and an up to date care plan assessment carried out. As a consequence the client with a progressive condition felt that he was now in possession of an updated care plan that would suit his current rather than previous needs.

Tim went on to outline how he saw the service develop in terms of creating a greater awareness for the purposes of ensuring that we develop a larger client base. He outlined the potential benefits of using social media such as Facebook and Twitter, the intention in the near future to present a press-release regarding our service, the development of a quarterly newsletter and continuing networking, giving presentations at relevant meetings and on-going liaising with the member societies of the Neurological Alliance. He pointed out that with increased public awareness and increased referrals, it was hoped that our client group would eventually result in the employment of a full-time advocate, that thereafter Fairway Advocacy might need to recruit more staff either on a part-time or voluntary basis. He outlined future plans around the challenge of achieving sustainable funding over a longer period with the ultimate objective of lobbying for some form of statutory funding. This would entail revisiting the legislation around statutory access as mentioned in the earlier presentation.

### **Service User Presentation: K.**

Maida next introduced a brief presentation from a current service user. Tim outlined the background to this service-user's care, given that K's condition affects his ability to communicate, K had been having difficulties with occupational therapy. They had come in June of the year to widen his doors, but this had not been done satisfactorily. K, who used a wheelchair, was constantly skinning his

elbows on the doorframe, sustaining cuts and bruises. Because of the narrowness of the doors, when coming out of one room to another, he had to negotiate a sharp angle and had fallen from his chair on more than one occasion. When K re-contacted Occupational Therapy, they said that they were not coming back to review matters as they had been in June and that there was no need and in any case there were not the resources to make any further changes. Tim indicated that he got in touch with Occupational Therapy at K's request and they had re-visited K's home the previous week and were now going back to the Housing Association to arrange a date for a further assessment, and further adaptations have been promised.

K then showed a brief film demonstrating the state of his house, the width of doors and the sharp angles that he had to turn through, but also the injuries that he had sustained to his elbows and to his head as the consequence of falling from his wheelchair. K's short presentation will subsequently be made available with K's permission, on the Fairway Facebook page.

Maida Gibson and the delegates thanked K for the excellent presentation that he had prepared, which was well received by all. Maida added that K's presentation was an indication if any of us needed one, of all the work that we have to do somewhere along the line, and the lack of statutory provision which is available, making our point that this is a service that is much much needed. She now passed over to Ian Bone to conduct the roundtable discussion.

## **Roundtable Discussion**

### **(Moderator Ian Bone)**

Ian had outlined several potential discussion points, these being:

- collecting evidence and evaluation,
- establishing informal partnerships,
- best pathways of referral,
- widening access to advocacy
- Long-term sustainability of a disability-based advocacy service.

A delegate from one of the attending advocacy services pointed out that brain injury and physical disability are part of their contracted workload. She pointed out that she had not brought any statistics along with her, but from the point of view of sharing information, they had evidence on the proportion of their clients with these conditions. She also pointed out that referral was often

problematic in that persons themselves often did not have an understanding of what independent advocacy was, and also there was perhaps an unwillingness or reluctance to access “just another service”, when they were uncertain as to what it might have to offer them. She pointed out that in terms of acquired brain injury, they had worked in conjunction with Headway, and ran a café (ABI) to allow people to drop in on a monthly basis not only to access services from Headway, but informally to find out about advocacy. Since the ABI café had been up and running, the numbers of persons accessing advocacy with brain injury or neurological conditions had been growing. She felt it was important to share information and also to share practice so that we could each learn from our own experiences, information on numbers seen as well as the pathways through which they had found their way to a specific advocacy service. She offered that Fairway Advocacy could get in touch and look at some of the partnership work that they were currently doing.

Another advocacy service delegate suggested that Tim could visit at any time. He pointed out that he could not give specific stats on the proportions of persons with brain injury seen, but would be delighted if Tim visited, to put these figures together. He also pointed out that his organisation did a lot of presentations and found that the presentations to Occupational Therapy (OT) Departments particularly helped. He indicated that a lot of statutory services out there were under the cosh to cut costs. He indicated that O.T. organisations welcomed advocacy, so that they could say that advocacy were involved and this would support their own particular aims to achieve funding for the adaptations that they were proposing. He also pointed out the help that advocacy could be to Social Work Departments, in ensuring that enough pressure were brought to bear to implement a justified recommendation. He emphasised the importance here in working together with these organisations in partnership, rather than necessarily being seen to be working against them.

The delegate from the third advocacy organisation pointed out that theirs was the largest in Scotland. She addressed the issue of having a waiting list. She pointed out that whilst this could be seen as evidence of need, it also was unfortunate. As a result their organisation had had to introduce eligibility criteria, looking at each individual and their circumstances whilst need was obviously a factor. She pointed out that the statutory obligation in terms of providing advocacy services under the Mental Health Act had to be met. She said that because of this, they could not always provide advocacy services to those with physical or neurological conditions alone, though obviously the level of need did come into making this decision. She pointed out that they covered several areas such as Renfrewshire and South Lanarkshire and that as a consequence they might have different waiting times in each area. She pointed out because of resources and demand; they were delighted to see a niche service such as Fairway Advocacy becoming established. A member of

one of the neurological charities outlined a specific case in relation to an individual with brain tumour and the difficulties that they had accessing support, as well as how this matter was resolved.

Next the issue of widening access to advocacy was discussed. The S.I.A.A. delegate addressed the issue of lobbying for any change in the current law. She felt that this was necessary and described work done in relation to legislation. She talked about Government guidance that patients should be in control and well informed of their condition and support available, but this guidance often did not indicate how this should be brought about and translate into practice. She pointed out the importance in accessing health and social care to ensure that patients are really at the centre of what is provided. She outlined the process of lobbying to Health Support Committees and M.S.P.s and to the Scottish Government. She outlined the lobbying in terms of Self-Directed Support saying that there was a need for advocacy within that legislation to really make sense of it. She mentioned there was reference to social workers pointing persons in the direction of advocacy if they felt that it was appropriate to do so but little more than this. She felt that there was work to be done in chipping away at current legislation and that the Scottish Government was receptive to having people's voices heard. She indicated however that translating this into action was the problem.

Finally, she concluded that SIAA were preparing a briefing for a Health and Support Committee around the findings of the Advocacy Map in light of a forthcoming discussion on the Mental Health Bill. This she felt needed to include further reference to advocacy as the right of statutory access enshrined in the Mental Health Act is not actually being observed.

Promoting the Fairway Advocacy Service was next discussed. It was pointed out by the Glasgow Disability Alliance delegate that over reliance on Facebook and the social media would be a mistake, as not all people had computer access and that their policy was still very much that of arranging meetings of service users with face to face contact. A service user concurred with this.

There was insufficient time to cover other proposed discussion points

### **Summing up: Maida Gibson**

Maida Gibson concluded the meeting, thanking all of those for attending, thanking individuals for sharing their thoughts and ideas, their enthusiasm for our project and the willingness especially amongst the fellow advocacy organisations and the S.I.A.A., to support our activities into the future. The meeting had obviously given us different and fresh perspectives for newer avenues to explore.

She emphasised that we could not be successful without the support and cooperation of those who had attended today, and thanked them for attending our official launch.

## Appendix:

### Organisations and individuals who registered.

Action for ME  
Advocacy Project  
Bobath Scotland  
Brain Tumour Action  
Care Worker  
Ceartas (Advocacy Kirkintilloch)  
Chest Heart and Stroke Scotland  
Circles (Advocacy – Forensic)  
Epilepsy Connections  
Epilepsy Specialist Nurse (GGCHB)  
Epilepsy Scotland (Lighthouse Project)  
Freelance journalist (Edinburgh)  
Glasgow Disability Alliance  
Health and Social Care Alliance (The Alliance)  
Headway  
Irwin Mitchell Solicitors  
Leuchie House  
MS Society  
McEwan Fraser Solicitors  
Parkinson's Society  
Parkinson's Specialist Nurse (NHS Lanarkshire)  
PDRU Southern General Hospital  
Progressive supranuclear palsy  
Robertson Trust  
Stroke Association  
Scottish Independent Advocacy Alliance (SIAA)  
Service users (Fairway and others)  
Stroke Association  
Tourette's Scotland  
You First (Advocacy Paisley)