

Report on the Joint Neurological Alliance of Ireland/Care Alliance Ireland conference “Always on my Mind”

The Joint NAI/CAI conference was held on Tuesday 10th March 2009 in the Radisson Hotel, Golden Lane, Dublin 8 as part of events to mark National Brain Awareness Week. Anne Winslow, Chair of NAI and CEO of the MS Society opened the conference. Anne spoke of the vital role played by family carers in neurological conditions and how this conference was aimed at highlighting and supporting the work they do. The title of this conference “always on my mind” was meant to convey the unique aspects of caring for a person with a neurological condition, where intellectual and personality changes can mean the person they once knew is radically altered. Anne outlined how important it is that carers seek support for themselves, a series of presentations and seminars throughout the day would outline the experiences of family carers as well as some of the supports available to them. The announcement the previous week of the Government’s decision not to go ahead with a National Carers Strategy was very disappointing to family carers who finally felt that they were getting the recognition they deserved. Anne noted that this should make our organisations even more determined to work on behalf of family carers and highlight the vital contribution they make to our society. As part of preparations for the conference today, NAI member groups asked family carers around the country for their experiences of caring for a person with a neurological condition. These were on display around the room and Anne encouraged attendees to read them during the day.

The first speaker of the day was Anne O’Loughlin, Principal Social Worker with the National Rehabilitation Hospital, Dublin. Anne is closely involved with Brí, an advocacy organisation for people with acquired brain injury. Anne has a long experience in working closely with family carers of people with neurological conditions. Her presentation “Neurological Conditions: The Carer Perspective” concentrated on the normal reactions and experiences of families when someone is affected by a neurological condition. Anne pointed out that each person has their own way of coping and that there are no golden rules. She highlighted a number of strategies that might help including taking a break, seeking support for yourself as a family carer and accepting offers of help. Anne outlined that she would expand on many of these points in her workshops “Looking after yourself as a family carer” in the afternoon.

The next speaker was Ann Stokes, Research and Policy Officer with Care Alliance Ireland. Ann’s presentation was threefold, to summarise research on the health of family carers, to present the main findings from Care Alliance Ireland’s quantitative study of family carers’ health and to share some initial findings from qualitative research on carers of people with Parkinson’s disease. Research has shown that caring can take its toll on the mental, emotional and physical health of family carers. The Care Alliance study “Health and Wellbeing of Family Carers in Ireland” published in 2008 was the most comprehensive piece of research on family carers in Ireland to date. Ann presented a number of findings from this study on the general health of carers, the impact of caring on health, specific difficulties experienced by carers and strategies used by carers to cope with the caring role. Overall, family carers report poorer general health than the general

population and significant levels of stress as a result of caring. Ann also presented preliminary findings from a research project which she has begun into the health and experiences of family carers of people with Parkinson's disease. Initial results show a significant effect of caring on all aspects of the family carer's life including the demands of physical tasks, constant caring role, social impact and emotional stress. This research will continue in the coming months.

Professor Chris Ward is a Consultant in Rehabilitation in Derby City Hospital UK. He first addressed NAI member groups at a joint conference on neurorehabilitation organised by NAI and the Department of Health and Children in December 2008. The title of his talk today was "What else besides caring? Family perspectives in long term conditions". Professor Ward outlined that the standard approach in neurorehabilitation is to focus on the individual with the neurological condition, the individual is perceived as having the problem and other family members are "carers". Doctors/professionals are the experts. In a family-centred approach on the other hand, there is focus on relationships, problems and solutions are shared and professionals are only part of the solution, along with family members. Professor Ward presented a number of vignettes from his experience in working with families of people with a neurological condition and very useful examples of the need to explore family narratives and relationships in the treatment of a neurological condition.

There followed a series of presentations by four member organisations, Headway, the Alzheimer Society of Ireland, the Huntingtons Disease Association and Acquired Brain Injury Ireland.

Richard Stables, Information and Support Manager with Headway presented preliminary results from a project which provides peer support for carers via teleconferencing. Initial findings show a number of advantages and challenges to using this approach. This approach can be particularly useful for people in isolated living situations or those not ready for face to face meetings. There is a significant onus on the facilitator to manage the session and make sure to close safely at the end of the call.

A number of family carers from the Alzheimer Society of Ireland gave an insightful and very moving presentation on the impact of caring for a person with Alzheimers disease. Denis Ryan, Chairman with the Huntingtons Disease Association of Ireland, outlined the family support services provided by the Huntingtons Disease Association of Ireland as well as a comprehensive outline of Huntingtons Disease and how it affects the individual and their family. The Huntingtons Disease Association provides a range of services including respite and carer breaks, family counselling, information and training from their family support officer and workshops for carers.

Acquired Brain Injury Ireland outlined their successful application to provide a structured training and support programme for family carers of people with acquired brain injury. The aim of the programme is "to increase carers knowledge of brain injury and skills required as well as improving their response to a family member's disability so that they can provide optimal care and cope with the emotional and psychological aspects of their role". The organisation proposes to provide 16 programmes across 8 geographical regions over a 2 year period.

Speakers from the morning session facilitated questions through a panel discussion before breaking for lunch. The audience were particularly interested in the research on family carers being carried out by Care Alliance Ireland and how insights into the experiences of family carers of people with Parkinsons disease are relevant to family carers of people with other neurological conditions.

After lunch, a series of workshops were held in parallel, with delegates having the opportunity to attend two out of the three workshops.

Workshop 1: Benefits and entitlements was facilitated by Marion McMahon of the Carers Association and provided detailed information as well as an opportunity to for individuals to address specific questions on benefits and entitlements for family carers.

Workshop 2: Looking after yourself as a Family Carer was facilitated by Ann O'Loughlin and Clare Walsh of the Social Work Team in the National Rehabilitation Hospital. Anne and Clare used some of the points from the morning presentation to provide an interactive and energetic discussion on how families experience a neurological condition and practical advice for day to day coping.

Workshop 3: Round Table facilitated workshop for service providers providing services to carers and family members. This was facilitated by Marie Lynch, Treasurer of Care Alliance Ireland and CEO of the Irish Hospice Foundation. This workshop was aimed at providing an opportunity for service providers to discuss the ways in which they provide support to family carers and any useful innovations or ideas that might be shared.

The concluding address was provided by Liam O'Sullivan, Executive Director with Care Alliance Ireland. Liam thanked all the speakers for their contribution to the day. He noted the emphasis on hope and empowerment in many of the presentations and the innovative and pioneering supports being developed by organisations, in partnership with family carers, to facilitate and support them in their role. Care Alliance will be working with its members over the coming weeks on developing an active response to the Government's decision on the National Carers Strategy. In addition, National Carers Week will take place from June 8th this year which will provide an important opportunity to highlight issues affecting family carers.

Mags Rogers, Development Manager with the Neurological Alliance of Ireland, noted the clear need for more research into the experiences of family carers of people with neurological conditions in Ireland. The current research project on family carers of people with Parkinson's disease will provide a vital blueprint for future research in this area and is warmly welcomed by the Neurological Alliance. Mags added her thanks to the speakers and advised that their presentations would be made available to download from the NAI website, www.nai.ie.

The conference concluded with a short film "Room to Manoeuvre" demonstrated by the Multiple Sclerosis Society of Ireland. The programme was made by the Disability Focus Group of the Dublin City Community Forum. Dublin Community Television was commissioned to do the filming and production, filming took place during November 2008.

This programme featured the adaptations made by an individual with multiple sclerosis to his home so that he could participate actively in household tasks and move about comfortably in a wheelchair. The film highlighted the significant positive benefits of adaptations as well as the cost impact and stressed the importance of planning, where possible, for the disabling effects of a neurological condition.

Over 90 delegates, including family carers, health professionals and service providers attended the conference and feedback on the day was very positive. In particular, attendees welcomed the opportunity to gain knowledge of the various services and supports available to carers and the involvement of family carers themselves in the presentations.