

CONFERENCE ABSTRACT

Planning for the Future With an Advancing Neurological Illness:

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Introduction: Neurological illnesses such as motor neuron disease, multiple sclerosis and parkinsons disease are recognised as life limiting illnesses. Voluntary organisations work closely with people living advancing neurological illnesses and are acutely aware of the needs of this group yet are rarely included in health research. We know that some people value planning ahead and that this becomes more important when diagnosed with a life limiting illness. Those working in voluntary organisations are well placed to begin conversations about the future with these groups.

Description: Neurological alliance of Ireland member organisations and one person with a neurological illness took part in a series of workshops to identify and explore the issues that people with advancing neurological illnesses face with regard to planning for the future.

Aim: To explore the issues with regard to planning for the future and develop a resource about planning for the future with a neurological illness.

Population and Stakeholders:

People with neurological illnesses, neurological illness organisations, healthcare professionals

Timeline: This work is underway and due for completion March 2017

Highlights: Getting a group of voluntary organisations together to discuss planning for the future with a neurological illness.

Development of a booklet about planning for the future with an advancing neurological illness

Sustainability: The booklet will be a resource that will be used by people, healthcare professionals and voluntary organisations supporting people with COPD

Transferability: The booklet hosts information about planning for the future that is applicable to all people.

Result: An information booklet tailored for people with an advancing neurological illness will be developed.

Conclusion: Voluntary organisations supporting people with advancing neurological illnesses host valuable information about the fears, concerns and wishes of the people they work with and are well placed to take part I research about this group.

Discussion: Engagement among all stakeholders to include patients and patient representative organisations is possible and can meaningfully be harnessed to inform the development of resources and services for people living with neurological illnesses.

Lessons Learned: Illness representative organisations can meaningfully input into the development of resources that impact upon the population that they represent.

There is an appetite among the chronic illness community to discuss future wishes.

Keywords: neurological illnesses palliative care planning for the future
