Living with chronic illness: Helping people make informed choices

Workshop May 5th 2017

Irish Hospice Foundation, Morrison Chambers, 32 Nassau Street, Dublin 2

The applicability of palliative care within the care of people with illnesses such as dementia, heart failure, COPD, chronic renal failure and advancing neurological illnesses is increasingly recognised within Ireland. Since 2010, the Irish Hospice Foundation (IHF), through the palliative care for all programme, have funded projects and worked with others in an effort to demonstrate ways that palliative care can be extended to these groups.

More recently it is being recognised that the voice of people living with illnesses should, and can be at the centre of all things that will have an impact on them. The degree of engagement with people with illnesses in the development of resources by organisations varies considerably in Ireland. There is growing acknowledgement that it is in fact crucial that people with illnesses be involved in such processes. There is also a growing body of evidence to suggest that people want to be involved in such work.

It is this shift in awareness that was at the centre of a meeting of over ten organisations held on May 5th 2017 in the IHF offices that coincided with the launch of the booklet “Conservative Care of Kidney Failure”. The meeting was a crucial step in identifying ways that organisations can work collaboratively to progress the provision of palliative care within the care of people with illnesses other than cancer whilst ensuring that the patient voice is at the centre of work being carried out.

Aim:
The aim of the meeting was to provide a platform to:

• Share current work and developments with regard to addressing the palliative care needs of people with illnesses other than cancer.

• Identify potential next steps with regard to addressing palliative care within the care of people with illnesses other than cancer.

• Encourage future collaboration among organisations involved in the care of people with illnesses other than cancer.
Representation:

Sixteen people attended the meeting representing voluntary organisations, professional bodies and healthcare workers. The patient representative organisations that were represented are listed below:

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<thead>
<tr>
<th>Cheshire Ireland</th>
<th>PSP Association</th>
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<tbody>
<tr>
<td>COPD Support Ireland</td>
<td>The Alzheimer Society of Ireland</td>
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<tr>
<td>Irish Kidney Association</td>
<td>The Irish Heart Foundation</td>
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<tr>
<td>Irish Lung Fibrosis Association</td>
<td>The Irish Hospice Foundation</td>
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The meeting was divided into two sessions (see Appendix I for meeting agenda). The first session was chaired by Marie Lynch, Head of Healthcare Programmes, IHF and consisted of five fifteen minute presentations. The session opened with an overview of the Assisted Decision Making (Capacity) Act 2015 which proceeded to be a common theme that threaded this session. This important piece of legislation promotes autonomy in all individuals and places a firm focus on the will preferences, beliefs and values of people. At its core, this legislation indicates that communication, participation and involvement of people with all illnesses and abilities is of utmost importance at all stages of their illness.

**The Assisted Decision Making (Capacity) Act 2015:**

As presenters discussed work carried out to date with regard to addressing palliative care for people with illnesses to include dementia, heart failure, COPD and advancing neurological illnesses it became apparent that an increase in awareness about this legislation and the role of palliative care within the care of people with illnesses other than cancer is required. In particular an increase in awareness in relation to future planning and having conversations early on in the illness trajectory so that will, preferences, beliefs and values are known. It was agreed that education for healthcare professionals about these issues in light of this legislation is also important.

**Barriers to Patient Involvement:**

Voluntary organisations noted the challenges experienced with regard to including people in work that has an impact on those who are living with long term life limiting illnesses. Those present consistently expressed being nervous about involving people with illnesses in their work. Although it was acknowledged that it is important to include people with illnesses, many expressed that they simply don’t know how to go about doing so.
Collaboration:

Those present agreed that there was scope to work together as a group to help bridge the patient – healthcare professional gap and identify patient information needs and represent them in a unified way. There was consensus that voluntary organisations should represent the patient voice, to ensure that people are aware of the available choices and that their choices are heard and respected especially within healthcare environments. It was acknowledged that unified messages from voluntary organisations are necessary to give people living with advancing illnesses a voice especially with regard to policy making and development of resources and services that people use.

The second session was chaired by Susan McKenna, Renal CNS, Cavan General Hospital. The booklet “Conservative Care of Kidney Failure” was launched at this session that was attended by Pat O’Connor, National Renal Office, HSE, who commended Susan for her work on completing the booklet. Margaret Fleming spoke about her experience of living with end stage renal disease and the need for information.

Conclusion:

This meeting provided those present with an opportunity to reflect on work carried out to date and explore how work that has an impact on people with long term life limiting illnesses can progress in the future. Attendees expressed valuing the time and discussion that took place and it appeared that the group was a source of support with regard to how individuals and organisations can meaningfully engage with the people that they are representing. There was consensus that there is scope to work together as a group to advocate for those people living with illnesses other than cancer and to seek to ensure that the patient voice is at the centre of information resources and services developed in relation to palliative care and planning for the future in the context of living with advancing life limiting illness and in light of the Assisted Decision Making (Capacity) Act 2015. Unified messaging has the potential to have an impact on the work of voluntary organisations as well as professional bodies and those working within healthcare that are engaging with people on a day to day basis.

Next Steps:

Based on this meeting and expressions as outlined, as a first step we will seek to hold a seminar that will address the issues raised. Expressions of interest in the development of a coalition of organisations with a remit to host a seminar at the start of 2018 should be sent to deirdre.shanagher@hospicefoundation.ie

This work was carried out as part of the IHF Palliative Care for All Programme that continues to seek ways to ensure that all people with life limiting illnesses access the care and support they need.
Appendix 1: Meeting Agenda:

Living with chronic illness: Helping people make informed choices

10.30-11.00  Tea/Coffee
11.00  Introduction
          Marie Lynch Irish Hospice Foundation

Session 1:  Helping People Make Informed Choices:

11.10  Assisted Decision Making (Capacity) Act 2015
          Deirdre Shanagher Irish Hospice Foundation
11.25  Heart Failure And Palliative Care
          Tracy Egan Irish Heart Foundation
11.40  Planning For The Future with COPD
          Ann Murphy Working group Planning for the future for people living with COPD
11.55  Living with a Neurological Illness — Planning for the Future
          Caroline Dooley Martyn PSP Association (Progressive Supranuclear Palsy)
12.10  Palliative Care and Dementia
          Dr Bernadette Rock The Alzheimer Society of Ireland
12.25  Discussion

Session 2:  Launch of Conservative Care of Kidney Failure Booklet:

12.45  Patient Perspective of Living With End Stage Kidney Disease
          Margaret Fleming Cavan/Monaghan Irish Kidney Association Representative
13.00  Development of Booklet
          Pat O’Connor National Renal Office
          Susan McKenna Cavan General Hospital
13.15  Launch of “Conservative Care of Kidney Failure” Booklet
          Mike Kelly Irish Kidney Association
13.30  Closing Remarks
          Marie Lynch Irish Hospice Foundation

Lunch