Palliative Care Inquiry
Fact Finding Visit to Ardgowan Hospice, Greenock
21 September 2015 1.00pm to 3.30pm

Attendees
Duncan McNeil MSP
Dennis Robertson MSP
Malcolm Chisholm MSP

The visit to Ardgowan Hospice had the following agenda:

13.00-14.15 Meet with Ladies and Men’s Support Groups; other Service users; Volunteers; and Carers
14.15-14.45 Meet with Representatives from HSCP, Ardgowan Hospice and IRH:
14.45-15.10 Visit In Patients Unit (IPU) – Meet Families
15.10-15.30 Meet with Clinical Colleagues to discuss Duty of Candour

Summary of Discussions with Support Groups, Service Users, Volunteers and Carers

- Some people have no familial support. Ardgowan offers them someone they can talk to.
- Ardgowan has an approach called “mindfulness”. This is a holistic approach that is all about relaxation.
- Believe that there is a misconception of what hospices actually do. Many believe that it is somewhere to go at the end of life when it is actually about things such as pain management. Many people at Ardgowan did not realise this until explained by Specialist Palliative Care nurses.
- For some the hospice was seen as a place of safety which can help alleviate the fears of the diagnosis and treatment that service users were living with.
- A large portion of the service users get access to and first hear about the hospice services through using its patient transport service. The transport service takes people to and from medical appointments and treatments. Many people either do not drive or find it difficult to drive following treatment. The transport service helps them make appointments. Accessing support to tell families about diagnosis and treatment as well as counsellors to assist with telling family about bereavement were also valued services at the Hospice. Assistance with practicalities such as organising wills was also helpful.
- One service user had valued the support so much they had also helped as volunteer when feeling well.
- Agreement from all that people need to get access to palliative care services much earlier. Participants commented that a lot of people are not receiving any until “end of life”.
- There was a general feeling that there is a lack of assistance once you have completed treatment. You may then only have contact with a specialist once a year but you can still have on going issues such as feeling low or lack of
mobility. Ardgowan provides somewhere that you can come and discuss these issues and also receive holistic treatments such as yoga and massage therapy. Some of the participants talked about accessing Ardgowan services and activities (such as jewellery making, and music) over many years, and in some cases this was as a family member as well as, later on, as a service user. It was also highlighted that Ardgowan services could be access after the death of the service user.

- Members heard that for men the Hospice could provide a place to talk about their treatment and symptoms in a way that they could not with friends and family—especially as they could talk to others who may have had similar health experiences.
- There was agreement that there needs to be a more “joined-up approach” to services. Currently you can go from your GP to a consultant to operation/treatment and then back to your GP. At each stage you need to explain the previous stages. There seems to be limited communication between GPs – Consultants – Hospices.
- There needs to be more use of holistic/alternative therapy as part of palliative care. Ardgowan Hospice promotes these practices and they help relax people which can have a follow-on benefit of keeping people out of hospital.
- Many felt that it was easier to speak about issues in a support group than speaking to your family. This included getting advice about day to day practicalities learned from others experiences. This was seen as important in improving well-being day to day.
- Also highlighted was how skills learned or addressed at the hospice such as mindfulness, talking about issues can improve well-being and keep people out of hospital.
- Need to promote use of both curative and palliative care systems.
- Confirmation that they had heard about Ardgowan Hospice through word of mouth and not at hospital.
- Each GP surgery should have an Ardgowan Hospice poster up.

Summary of Discussions with representatives of Inverclyde Health and Social Care Partnership (HSCP), Ardgowan Hospice and Inverclyde Royal Hospital

- In an acute setting the palliative care journey can differ from specialty to specialty. Clinical specialists in site specific roles seem to be moving out of community into more centralised locations. This results in the loss of a community link.
- Agreement that there is still a huge lack of understanding of what palliative care is. This is not helped by the very little training provided to junior doctors.
- Whilst a hospital may have a specialist palliative care nurse they feel their ability to make a significant difference is limited as they tend to spend a lot of their time “fire-fighting” clinical work.
- There is a push for palliative care to be more widely provided for people with non-cancer related illnesses, such as for people with renal conditions who have decided they no longer want to undergo dialysis. However there is still a struggle enabling people with conditions such as heart disease to be identified as benefitting from palliative care as they may not realise the trajectory of their condition. Patients with no malignant conditions also may have their own
services and knowledge which means that they may not know about or consider palliative care as being of benefit to managing their condition.

- Outreach services in Greenock are provided by Ardgowan. Ardgowan run 4 specialist nurses that work Monday to Friday, 9 till 5. They are currently looking at ways to make this a 7 day service. These specialist nurses work alongside district nurses. Macmillan provides a welfare service within Ardgowan Hospice that helps people traverse the welfare system.

- Belief that the timeliness of a referral into hospice care can have a direct impact on the life expectancy of a person.

- Feeling that there seems to be some “gatekeeping” happening in hospitals around gaining access into palliative care system. Agreement that late referral can result in a worse prognosis for some.

- Belief that cancer diagnosis has good signposting to palliative care but other conditions still need to catch up.

- Agreement that while a SVQ in palliative care may have some advantage, it is local networks that really help. Social workers are involved in palliative and end of life care every day. There doesn’t always need to be a medical process. Best outcome is a mixture of both medical and social care.

- There was discussion about the importance of service users being able to tap in and out of hospice services. The concept of ‘inside out’ delivery of palliative care services was discussed- at Ardgowan this involved hospice services being delivering in the home or at other venues which services users can access more easily than the hospice in Greenock.

- Worry among palliative care providers that people will get bogged down in the definition of palliative care. While it is important for people to understand what it is, it is more important to ensure that the service is being provided. Don’t want to end up doing service users a disservice. It was highlighted that sometimes end of life care and palliative care were mixed up meaning that services were not made available to potential service users until very late on.

- Argowan is training those in the community, such as Hairdressers, who may be able to assist in signposting potential service users to the hospice and its facilities. Similarly there were opportunities for care assistants to receive training given their contact with people in the community.

- Also important was building in sustainable community support for the hospice e.g. local care service firms provide a discount and free MOTs to volunteer drivers who support the hospice’s free patient transport service.

Summary of Discussions with patient families.

- Had found it easy to gain access to support.

- Patient was initially getting visits from a district nurses. Nurse originally assessed patient and arranged for mobility aids to be put in place via the Centre for Independent Living. Advised hospice care was not yet required but they would carry out a further review when the family felt it may be needed. When family contacted for further review this was carried out and the GP was advised of the outcome.

- GP then contacted Ardgowan Nurse who visited, recognised that hospice care would be suitable and recommended it to the family. The patient was admitted to Ardgowan Hospice the next day.
- Felt the care and compassion received was “phenomenal”.
- Members heard about the range of agencies that were involved in the patient’s care. The family highlighted concerns about whether all the health care providers involved in a patient’s care actually talk to each other – was it as joined up as it could be.
- The family highlighted the important role of family support and care in enabling the patient to remain at home.

**Meeting with clinical colleagues.**

As part of the Committee’s scrutiny of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill, members discussed Duty of Candour with clinical colleagues. The note for this session will be provided to members ahead of the Committee’s meeting on 6 October 2015, when the Committee will next take evidence on the Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill.