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| Organ Donation Initiative | 19th April 2016 |
| Corporate Policy and Resources For decision | |

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| Linkage to Council Strategy (2015-19) | |
| Strategic Theme | Resilient, Healthy and Engaged Communities |
| Outcome | Raising awareness of Organ Donation Service |
| Lead Officer | Liz Johnston |
| Cost: (If applicable) | n/a |

1.0 Background

At the Council Meeting on 26th January, Members received a presentation on the Organ Donation Service, Council agreed to support the initiative and that a report be prepared on how to implement some of the suggestions put before Council by the delegation. The aim is to increase awareness of the service provided in Causeway Hospital and to promote the importance of becoming an organ donor.

2.0 UK Facts –

- Almost 17 million adults in the UK haven't decided whether to donate their organs after death.
- 4.1 million people in the UK, who do want to donate their organs when they die say they haven't talked to a loved one about that decision.
- across the UK there are 10,000 people in need of a transplant.
- The UK has one of the lowest rates in Europe for families consenting to organ donation. In 2014/15 only 58% agreed to donate their family members' organs after they died.

Northern Ireland Facts

- Families are not aware of their loved ones being on the register. It is recommended to discuss with GP, family member and to ensure that all details are on the official register.
- Numbers and waiting lists in Northern Ireland stipulate that over 200 people in this country are waiting for an organ donation, 19 will have passed away before they receive their transplant.
- It costs £30k per year to keep someone alive on dialysis, and they can wait for approximately two years. 160 of those waiting are on this list with costs to the health service escalating as they wait for donors to come forward.

3.0 Recommendation

There has been engagement with the Organ Donation team based in Causeway Hospital on the support which Council can provide. The facts which those who advocate organ donation in Northern Ireland face on a daily basis has also been considered. Members are invited to consider supporting the Organ Donation Initiative as follows:

- To provide the Organ Donation Team with an information stall at key events led, sponsored and managed by Council.
- To receive cards, leaflets and posters to distribute in Council premises: -
 - Corporate Buildings, Town Halls, Leisure Centres, Arts Centres and Museums, Community facilities.
- To request NILGA to include information on Council's support in its Newsletter, seeking the support of other Councils.
- Promote Council's support with a Press Release and Photo of Councillors, with donor cards, who support the initiative.
- Raise awareness by Member attendance at the Gala Dinner in Tullyglass Hotel, 8th September 2016.
- Include promotion on Council website and link with Organ Donation website.

Attached, for members convenience, is copy of the presentation made to Council on 26th January 2016 by the Specialist Nurse – Organ Donation, based in the Causeway Hospital.

Council meeting 26th January, 2016

My name is Mary McAfee and I'm a Specialist Nurse- Organ Donation based in the Causeway Hospital. My employer is NHS Blood & Transplant who are the organisation responsible for the matching and allocating of donated organs in the UK. It is also responsible for the provision of a reliable, efficient supply of blood in England and North Wales, and providing tissues to the NHS.

N.Ireland is one of 12 Organ Donation Services Teams across the UK with 14 Specialist Nurses including 2 Team Managers covering all 5 HealthTrusts. We provide a regional on call service for all acute hospitals in N.I. so that every patient who dies in circumstances where donation is a possibility their families will have the opportunity to make a decision regarding Organ Donation.

We have an important role in supporting bereaved families, and ensuring they are offered donation at the right time by a skilled professional who will do so in an empathetic and sympathetic manner. We will then coordinate all aspects of the donation to honour the wishes of the bereaved and their families.

Each trust has a Clinical Lead- Organ Donation & Organ Donation Committee to oversee organ donation activity within our acute hospitals.

What is organ and tissue donation?

It is giving an organ or tissue to help someone who needs a transplant.

One donor can save or transform up to 8 lives and many more can be helped through the donation of tissues. But this relies on donors and their families agreeing to donate their organ or tissue.

Nationally fewer than 5,000 people each year die in circumstances where they can donate their organs; they are patients who are usually cared for within our Critical Care Units. This is a small group of patients so it is vitally important that every opportunity is explored.

There are three different ways to donate:

Donation after Brain stem death - Those patients who are confirmed dead through neurological criteria (Brain Stem Death testing)

Donation after Circulatory death - can be an option where there is a planned withdrawal of life-sustaining treatment and donation will only occur after death has been certified following the loss of cardio/respiratory function.

Living donation - Whilst you are still alive you can choose to donate a kidney, or a small section of your liver.

People die every day in the UK because not enough organs are available for transplantation so we need to do everything we can to make every opportunity for organ donation count

10,000 patients across the UK are in need of a transplant.

162 patients are currently waiting in N.I...

10 people are currently waiting in the Causeway Coast & Glens Council area.

Transplantation remains the gold standard treatment for those individuals suffering end-state organ failure. The harsh reality is that 3 people die every day in the UK waiting (15 patients died last yr in N.I.). Yet 1 in 3 adults haven't considered organ donation or decided whether they want to be a donor.

The UK also has one of the lowest rates in Europe for families consenting to Organ Donation and in 2014-15 only 58% agreed to donate after their loved one had died. Last year 88% of families agreed to donation when their loved had registered on the NHS Organ Donation Register but this fell to 43% when their wishes were not known. The most common reason for families declining is not knowing what their loved one's wishes were? This is a stressful and emotional time for families so it is important that they really know and understand what the wishes of the person were. It can also make their decision a lot easier when they are trying to deal with their loss.

In 2013, N.I. saw an increase of 81.8% in deceased donors over the previous 5 years and this continues to rise yearly. It was a landmark event and is

testament to the changes made nationally at every level in hospitals to deliver this, to the commitment of critical care and emergency department staff to donation, and most of all to the generosity of donors and their families.

Causeway Hospital has made a significant contribution to our recent achievements. Since 2010, 11 individuals and their families consented to donation and changed the lives of 31 patients. Regionally and nationally we saw the highest number of donors- 48 & nationally- 1282 donors in year 2014-2015.

However we must do more, because patients continue to die needlessly waiting for an organ transplant.

78% of the pop would take an organ if they needed one but only 34% have registered to donate on the NHS Organ Donation Register.

On 21st January there were 26% (37,182) residents in our Council on the NHS Organ Donation Register.

Regionally 35% of the population are on the NHS Organ Donation Register.

To raise this number we really need everyone to understand the importance of not being complacent and get to the point where Organ Donation is high on the list of important personal conversations that we routinely have with our loved ones. Reluctance to talk about donation means many healthy organs that could be donated aren't. Key reasons for this reluctance is discomfort around talking about death and not wanting to upset family members.

If we are to make the UK's OD record among the best in the world we need to encourage everyone to discuss organ donation with their family and friends and cultivate a culture where everyone is proud to donate when they can. Anyone can register on the ODR. Age, religion, many illnesses or long-term conditions are not a barrier.

You can join the ODR by:

Going to www.organdonation.nhs.uk

Ringling 0300 123 23 23

Texting SAVE to 62323

I would like to acknowledge the excellent support received from Coleraine Council in recent years to promote organ donation within the Borough.

A Commemorative Event was held at the Causeway Hospital on 15th Oct, 2014 and a bench was dedicated to recognise our local donors and their families who bravely donated their organs to give others the gift of life.

The Council also wrote to the Education Minister to ask if organ donation and transplantation could be introduced into our children's curriculum.

In collaboration with the H&W officer, donor families and transplant recipients, we attended the Portrush Air show to promote donation

Future CC & Glens Council events could continue to raise OD awareness.

The Trust has recently introduced Organ donation stickers on their vehicles, would this be something the Council would consider for their vehicles?

Online bulletin boards discussing organ donation & transplantation can be a useful tool to reach the wider community and possibly exploring the use of the Council website to link into N.I. Organ donation site

So unless there is a revolution in attitudes to organ donation people waiting for a transplant people will continue to die unnecessarily.

I would now like to introduce Alexia McCooke - the mother of an organ donor who is very bravely coming to speak from a family's perspective.

Next we have Lucia who is an organ donor recipient. At 8 years of age Lucia was diagnosed with auto immune hepatitis and acute liver failure. She has kindly come along tonight to tell her story and highlight the importance of organ donation.

