Meeting of Lanarkshire NHS Board: 28 August 2019 Lanarkshire NHS Board Kirklands Fallside Road Bothwell G71 8BB



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SUBJECT: "End of Life Support - Carer feedback"

# 1. PURPOSE

This paper is coming to the Board:	
For approval	
This film shares carers' experience leading up to and following the expected death of Mr Stuart Kelt at University Hospital Wishaw. Mr Kelt had Downs Syndrome and learning disabilities and was supported by the <i>Potential Living</i> organisation based in Motherwell.	
The film shows excerpts from interviews with members of the team; it demonstrates the importance of specialist bereavement care at what can often be a very difficult time for carers and relatives. It also shows the benefits of spiritual care in supporting carers through anticipatory grief as it often helps the bereaved look back at the time leading up to a death as a time where they celebrated the life and the significance of being able to share memories of the dying person. Good bereavement care helps people to prepare for and to deal with their loss and their grief, and allows people to find a 'new' normal after a death.	
Potential Living has been providing support to individuals in Lanarkshire with a variety of support needs and disabilities for well over thirty years. In partnership with social work and health, they work for many local people, sharing with them their journey towards not only fulfilling their potential but also enjoying a rich, happy and full life. Their aim is to ensure that the people they work for are empowered to be in charge of their own lives. They believe in the personalised delivery of services in a way that always has the individual at the centre, with bespoke support arrangements tailored to meet their own unique needs and personal circumstances.	
https://vimeo.com/nhslanarkshire/download/352889499/ae075a548a	
2. ROUTE TO THE BOARD	
This paper has been:	
Prepared Reviewed Endorsed	

By the Bereavement Care Group, and reviewed by the Corporate Management Team.

#### 3. SUMMARY OF KEY ISSUES

Empowering carers at end of life: This film captures the importance of supporting carers/relatives to provide appropriate levels of care at the end of life. The key phrase used throughout our conversations was 'partnership', and the film demonstrates the impact of a poor experience and its influence on how they perceive all inpatient care, the power of good person-centred care and partnership working in building a bond of trust with members of the community.

**Bereavement Care:** Approximately 6,000 people die in Lanarkshire each year. It is thought that on average at least 4 people experience deep grief following a single death. This would mean that 24,000 citizens (6,000 x 4) are affected significantly by grief and loss each year. This equates to just under 70 citizens every day.

Statistics from the Listening Services delivered by Spiritual Care teams across Scotland, show us that if grief and loss is not 'processed' through caring and supportive networks or opportunities to be listened to; it then becomes a long term underlying issue and is often the root cause of other chronic conditions such as depression, sleep disorders, anxiety and stress.

#### 4. STRATEGIC CONTEXT

This paper links to the following:

Corporate Objectives	AOP	Sovernment Policy	$\boxtimes$
Government Directive	Statutory Requirement	AHF/Local Policy	
Urgent Operational Issue	Other		

# 5. CONTRIBUTION TO QUALITY

This paper aligns to the following elements of safety and quality improvement:

# Three Quality Ambitions:

Safe	Effective	Person Centred	

### Six Quality Outcomes:

Everyone has the best start in life and is able to live longer healthier lives; (Effective)	
People are able to live well at home or in the community; (Person Centred)	
Everyone has a positive experience of healthcare; (Person Centred)	
Staff feel supported and engaged; (Effective)	
Healthcare is safe for every person, every time; (Safe)	
Best use is made of available resources. (Effective)	

#### 6. MEASURES FOR IMPROVEMENT

No one dies alone (NODA): is an initiative, adopted from Compassionate Inverclyde, which will aim to ensure that no-one dies alone in Lanarkshire (unless it is their express wish). We are beginning a community building project to train and mobilise volunteers to accompany people who have little or no support network at the end of life. We will also use materials developed within our 'Addressing the Great Taboo' workshops which enables people to discuss dying, death, grief and loss in a way which helps normalise topics surrounding death.

Lanarkshire Listening Service: we will track the amount of sessions where the key underlying issues are related to death, loss and grief. Bereavement Care for staff is also important, especially as it will have a significant impact on people who are already stretched or have low resilience. This will be a key measure as we begin preparations to establish a new Staff Care service.

#### 7. FINANCIAL IMPLICATIONS

No one dies alone - Non-capital expenditure for the pilot of this project is estimated at £2,500 (mainly for volunteer travel expenses, training and supervision – this will be met from Spiritual Care budget for the pilot) and will be included in a future business case which will be generated as output from the pilot.

NHS Lanarkshire Listening Service – Non-capital expenditure to expand this service in GP Practices is estimated at £1,250 per annum for a weekly session, again mainly for listeners' travel expenses, training and supervision. This will be part of a separate project business case.

### 8. RISK ASSESSMENT/MANAGEMENT IMPLICATIONS

Any associated issues will be managed, recorded and reported in line with NHS Lanarkshire Policies and Guidelines.

### 9. FIT WITH BEST VALUE CRITERIA

This paper aligns to the following best value criteria:

Vision and leadership		Effective partnerships 🔃 Governance ar		Governance and	
				accountability	
Use of resources	$\boxtimes$	Performance Management		Equality	
Sustainability	$\boxtimes$				
Management					

10.	$\mathbf{E}\mathbf{Q}$	UALITY	AND D	IVERSITY	<b>IMPACT</b>	ASSESSMENT
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Yes	
No	Will be completed for No one dies alone Project

### 11. CONSULTATION AND ENGAGEMENT

The outline of the No-one dies alone Project will be developed with community volunteer organisations, and the project board will have a representative from the NHS Lanarkshire Public Reference Forum.

### 12. ACTIONS FOR THE BOARD

The Board are asked to:

Approval	Endorsement	Identify further action	
Note	Accept the risk identified		

# 13. FURTHER INFORMATION:

For further more detailed information or clarification of any issues in this paper please contact:

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12<sup>th</sup> August 2019