

with distressing symptoms that are amenable to palliation using familiar basic measures. Increased preference for care at home but increased difficulty in harnessing usual forms of support for patients (families, health & social care professionals for home support, admissions to hospital, care home placement) and for families (home support, bereavement support, being able to be present when someone is ill or dying). Increased need for inpatient care for some dying people but difficulty in allowing families (i.e. whoever is close to the person) to support them.

Key lessons learnt - Basic palliative care measures work well in COVID-19, including drugs for symptom control. Most palliative care units are not well set up to control transmission. Keeping visitors away makes it harder to provide good care for patients and much harder to support families, particularly when it comes to communicating with them and providing support around the time of death, and there are factors that have to be set alongside infection prevention & control principles in deciding what can be permitted. Some historic rules are unnecessary; for instance we can if necessary repurpose drugs from one care home resident to another if we have to, provided we do it carefully, and we can allow family members to give injected drugs if we offer the right support. We know a bit more about what really matters (good medical care, good symptom control, but also individualisation, human presence and flexibility in approach) and what doesn't (being too risk averse to protect ourselves). The experience of death, dying and bereavement has been much worse for very many families in this pandemic because people have been so isolated from each other. Communication about what we are doing in end of life care and why matters.

Opportunities as we recover - We can build on the points above – do more of what adds value to people's lives and less of what doesn't, to state the obvious. To this end we have to get better at measuring what adds value and at sharing that information with those who need to know – with those engaged in the care of the person, and aggregated with those who design and run systems for caring. We can see the need for palliative & end of life care as being at the heart of health & social care, rather than being an added extra as if only needed when all else fails. It is normal, and we can make a norm of its inclusion and embedding in planning and in service delivery. This includes planning for future pandemics even as we recover and learn from this one. Planning for the human, the personal, takes time and reflection but will equip us better to make urgent responses that reflect our shared need for

Challenges and Risks - If we omit to learn what this pandemic teaches us about people's end of life care needs, we will face future lethal crises – pandemics and others – having again to make plans ad hoc. The biomedical aspects of this can be done quickly, as we have shown, but others need more planning. And we cannot risk planning, and caring, only for the physical when we know the importance and the interconnectedness of the social, the psychological and the spiritual domains of health, all of which have been relatively neglected at times in the last year.

Priorities - Know what matters and do what adds value. Don't do what doesn't. Embed measurement of this at the individual level in people's care. Use this to get better at identifying who needs palliative and end of life care, when, and where, identifying what their priorities are, and at identifying those experiencing bereavement. Build robust systems for responding to these people's needs. Plan well for future crises so that they don't throw us off course. Communicate well about these plans.

From: **Name Redacted** <Name Redacted@gov.wales>

Sent: 11 February 2021 08:36

Name Redacted

Name Redacted <Name Redacted@gov.wales>; Kamalan, Chrishan (HSS - DHP Public Health) <Chrishan.Kamalan@gov.wales>; **Name Redacted** (HSS-DHP-Population Healthcare)