P.2018/24 PRC Lett Com

Policy & Resources Committee

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8th May 2018

Dear Sir

P2018/24 Requête – Assisted Dying

I refer to the above requête which is scheduled for debate by the States on 16th May 2018. Individual members of committees will from time to time have differing views. On this occasion, the Committee is mindful that two of its members are requérants, namely Deputy Gavin St Pier and Deputy Lyndon Trott. They have recused themselves from consideration of the enclosed consultee responses and development of this letter of comment.

The Committee acknowledges that this is a subject that stirs great emotion and is generally a matter of personal conscience. However it is exercising its right under Rule 28 (2)(b) of the Rules of Procedures for the States of Deliberation and their Committees to "set out its opinion in a letter of comment, appending thereto the views of all Committees so consulted".

Members thank the consultees for their factual and objective responses, the content of which does not require reiterating in this letter of comment.

The Committee's opinion on the scope and timing of the requête in light of the issues brought forward by Committees brings it to the following conclusions –

1. The requete's ambition does not align with the current 23 priorities of the Policy & Resource Plan and as the Committee is mandated by the States to coordinate and manage the Plan it cannot recommend the requête's support;
2. The requête will likely lead to resource intensive investigations, working parties, consultations and similar which given the finite resources of the States will draw from other prioritised areas which consequently will have to be deprioritised;
3. The requête is currently very general and many issues could require formal legal advice. It has not been prudent to undertake research into these many different and complex issues as the research might well depend upon which, if any, of the factors set out in paragraph 2 of the requête are generally supported or formally

resolved by the States. However it is clear to the Committee that working through legal issues will be lengthy and expensive.

In summary it is the unanimous view of the Committee (sitting without its recused Members) that whatever one's personal beliefs on this contentious matter, it would be poor governance to support the requête and then to not discharge it because it is not resourced or funded. These requirements are not quantified in the requête. The Committee has just released the update to the Policy & Resource Plan and it is clear additional resourcing is required to meet the priorities already established by the States. The consequence of this will be laid before the States for debate in the 2019 Budget. To resource and fund the requête appropriately, if it is successful, may therefore require de-prioritisation of other government policy work streams at that time.

Yours faithfully

T. J. Stephens

Deputy T J Stephens
Social Policy Lead
Policy & Resources Committee

Enc: Consultation responses from –

- Committee *for* Health & Social Care inc GMC response
- Committee *for* Home Affairs
- Committee *for* Employment & Social Security

Committee *for* Health & Social Care

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23 April 2018

Dear Deputy Stephens

Assisted Dying Requête

Thank you for requesting the comments of the Committee *for* Health & Social Care in relation to the Assisted Dying Requête.

This response focuses solely on the direct implications of the proposals on the Committee's mandate, as well as providing background information in respect of the current palliative care services available. It does not focus on the broader social and ethical considerations. Individual members of the Committee will, of course, express their personal views during the course of debate.

The Committee would note that the below is not intended to be exhaustive. It has been prepared in the time available and would need to be, should the States approve in principle the introduction of Assisted Dying, expanded upon further by the proposed Working Group.

Dying Matters Week

Firstly, the Committee would highlight that debate of the Assisted Dying Requête is scheduled to coincide with Dying Matters Week. The week is a national initiative which seeks to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Discussions about death are invariably difficult, however a reluctance to do so impacts significantly on the experiences of people who are dying and bereaved.

The compassion, mutual respect and honesty with which the Assembly will undoubtedly approach this debate must extend more broadly to how we, as a community, engage with the subject of death. The Committee acknowledges, respects and indeed shares the broad range of views held across the community in respect of Assisted Dying, but hopes that all

members of the Assembly can give their support to the spirit of Dying Matters and the importance of all islanders taking opportunity to talk to their families about their personal end of life preferences. Only by having these conversations are we, as an Island, best able to support islanders at the end of their lives to die where and how they wish.

Irrespective of any decision made by the Assembly regarding Assisted Dying, there must be a general commitment across the States, the health and care system and the wider community to engender a culture where death is recognised as a natural part of the life cycle which people feel comfortable talking about.

Current Palliative Care Provision

Dying well and end of life care is a vital part of health and care provision across the Bailiwick focused on dignity, compassion and choice. Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness. It focuses on preventing and relieving suffering through early identification, careful assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It is the responsibility of all staff employed within Health & Social Care services, partner organisations and commissioned services within Guernsey and Alderney and there are excellent examples of multidisciplinary working across the islands.

As part of the 2004 States' debate on Voluntary Euthanasia, the States directed the then Health and Social Services Department to report back on palliative care. The resultant Policy Letter was presented to the Assembly in 2007 and set out a phased implementation plan to support and ensure "palliative care of the highest standard." This has in the intervening years been implemented, subject to evolving best practice.

The Committee employs a nurse led Specialist Palliative Care Team, incorporating senior nurses and a social worker, who work closely with the doctor responsible for the patient's care. Additionally, a Consultant in Palliative Care from Southampton visits Guernsey for two days a month to undertake clinical visits and provide teaching and input into project work. This is further supported by 24/7 Consultant telephone support from Southampton. Importantly, the Committee employs on a sessional basis an End of Life Care Facilitator.

This post, over the last two years, has led a programme of improvement around end of life care which has focused on understanding the practical experiences of islanders and the families. This year steps are being taken to further develop individualised care for people in the last days of life, focusing on the Five Priorities of Care for the Dying Person. The priorities are detailed below and their application locally were the subject of a Safer Everyday presentation earlier this month. This Presentation may be found at https://gov.gg/safereveryday.

- **Recognise** - The possibility that a person may die within the coming days and hours should be recognised and communicated clearly, with decisions about care made in accordance with the person's needs and wishes reviewed and revised regularly.

- **Communicate** - Sensitive communication should take place between staff and the person who is dying and those important to them.
- **Involve** - The dying person, and those identified as important to them, are involved in decisions about treatment and care.
- **Support** - The people important to the dying person are listened to and their needs are respected.

  Plan and Do - Care is tailored to the individual and delivered with compassion – with an individual care plan in place. This priority includes the fact that a person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised.

The small but dedicated Specialist Palliative Care Team is well respected and provides support and advice to health and care professionals across the Island caring for terminally ill patients, focussing on integrated care centred around the needs of patients and their families. The Committee would stress and highlight the areas of excellence within current palliative care services and no-one should be under any doubt of the professionalism and commitment of the staff involved and the invaluable nature of the work that they undertake.

However, in line with other areas of HSC's service delivery, continued consideration needs to be paid as to the quality and scope of services available in order to better support Islanders and their families. Irrespective of any decision made by the Assembly in respect of the merits or otherwise of Assisted Dying, there must be continued recognition of the importance of high quality palliative care and the provision of individualised care, along with the need to constantly evolve in line with best practice. Such consideration will take place as part of the Committee's development of the Partnership of Purpose.

Doctrine of Double Effect

The Committee has received questions on the doctrine of double effect. It must be stressed that palliative care is designed neither to hasten nor to delay death, rather it seeks to achieve a death which is as natural as possible. The primary aim of practitioners in deciding appropriate palliation through treatments and intervention is symptom management in accordance with guidance and the law. Individualising care to the needs and views of individual patients is routine patient management, drawing upon best practice and evidence. Individualising care does not include the conscious decision to hasten death.

Proposed Capacity Law

As recognised by the Requêrants, the introduction of capacity legislation is a fundamental requirement which must be successfully implemented before any regime permitting Assisted Dying could be introduced. Broadly, the Capacity Law will protect and empower islanders over 16 who may lack capacity to make their own decisions where possible, to

allow them to plan for the future and, if they lack capacity, to ensure that decisions made on their behalf respect their basic rights and freedoms. The fundamental principle underpinning the legislation is to empower people to make decisions for themselves wherever possible. Specifically, it enables those with capacity to make fundamental decisions about their future in relation to their health and welfare matters either through Lasting Powers of Attorney or through Advance Decisions to Refuse Treatment.

The drafting of the relevant legislation has been identified by the Committee as its highest drafting priority, and it is grateful that the Assembly has recently endorsed the importance of the Law's drafting. The Law will, in accordance with the extant States' Resolution,

- set out a statutory test to decide whether a person has lost capacity in relation to a particular decision,
- establish the best interests' principle in relation to making decision on behalf of people who lack capacity,
- introduce Lasting Powers of Attorney (which permit a person to nominate one or two other people to act on their behalf when that person loses capacity in relation to property and finance matter and/or health and welfare matters),
- introduce Advance Decisions to Refuse Treatment (which permit a person with capacity to make a decision to refuse specified medical treatment which is required when they lack capacity to decide), and
- introduce an equivalent to the Deprivation of Liberty Safeguards adopted in the UK.

It is uncertainty in respect of this final point within the UK, ensuring that the detention of people lacking capacity is approached in a manner which is compliant with the European Convention on Human Rights, which has delayed the introduction of the legislation locally. However, having reflected upon the work of the Law Commission in respect of this matter and HM Government's subsequent responses, the Committee will be progressing proposals during the course of this year to develop a framework which efficiently and effectively protects the rights of individuals who are treated and accommodated as part of the overarching Capacity Law. Based on current timelines, the Committee would anticipate consulting with key stakeholders during the second half of this year with the resultant Projet de Loi being presented to the Assembly in early 2019.

The Committee has to stress that while all laws require a structured implementation with scheduled opportunity for review and assessment reflecting on its practical application, the importance of this process for the Capacity Legislation cannot be overestimated. The Committee would fully concur with the Requêrants that appropriate and effective capacity legislation is a prerequisite to any legislation permitting Assisted Dying, but would go further and suggest that only once the legislation has successfully been in place for a period of several years and is demonstrably effective and embedded across health and care practices, should it be considered sufficiently robust so as to be used in respect of any Assisted Dying regime. The practical experiences within England and Wales have illustrated the challenges associated with Lasting Powers of Attorney and while the

Committee is seeking to learn from the experiences of other jurisdictions in the preparation of local legislation, the Committee would want, as far possible, opportunity to evaluate the introduction of both Lasting Powers of Attorney and Advance Decisions to Refuse Treatment before practically engaging with an Assisted Dying Regime.

The Committee recognises that it has been suggested that any legislation introducing assisted dying regime could include specific provision regarding capacity, supported, as appropriate, by Codes of Practice or similar guidance rather than reliance on the introduction of general capacity legislation. While this may be possible in principle, the Committee would strongly caution against such an approach, noting the potential challenges of seeking to introduce capacity provisions in two separate statutes in parallel, and inability to take opportunity to learn from practical experience.

Any Assisted Dying regime must incorporate significant safeguards so as to protect the most vulnerable in our society both through clear and established criteria and processes and, if necessary, the creation of further criminal offences. Current arrangements surrounding the safeguarding of adults is at a relative state of immaturity locally. While this is a priority for the Committee and initiatives such as the Adult Multi Agency Safeguarding Hub are already beginning to have benefits, the Committee would wish to see these further developed before the implementation of an Assisted Dying Regime.

Acknowledgement of the practical considerations surrounding registration bodies and broader regulation/ governance;

The Committee has approached, via the Chief Nurse and the Medical Director, the Nursing and Midwifery Council (NMC) and the General Medical Council (GMC) to understand the possible implications of an Assisted Dying regime in respect of the registration of local health and care professionals and the guidance offered to them. Both the NMC's Code: Standards of Conduct, Performance and Ethics for nurses and midwives and the GMC's Good Medical Practice Guide set out clear guidance for clinical practice based on the highest professional and ethical standards and clarification is being sought on whether the regulatory bodies would consider participation within an Assisted Dying regime reconcilable with the duties imposed on individual practitioners. At the time of this response, the Committee has not had a response from the respective regulatory bodies.

Irrespective of the broader registration concerns, the Committee would stress the importance of conscientious objection. On the matter of Assisted Dying, the Committee believes that it is important to recognise, in addition to the patient's dignity and views, the personal views and conscience of health and care professionals and protection of this should be accepted in any regime.

As the Assembly is aware, the development of regulation across health and social care is a priority for the Committee. Regulation ensures public safety by establishing high standards of practice and behaviour through systematic measures to monitor, maintain and improve quality. The Committee is conscious that any Assisted Dying Regime would need to be

subject to robust clinical governance and regulation, either through a broader regulatory regime incorporating appropriate considerations or a specific framework in place for Assisted Dying. The Committee intends to report to the Assembly on a regulatory regime later this year.

The Committee would separately note, conscious of its duty of care towards health and care staff, that it is possible under s.9 of the Offences Against the Person Act 1861 for murder or manslaughter committed by a British citizen outside of the United Kingdom to be tried and punished in England. This would mean that any British citizen (including a medical professional) could be prosecuted in England for aiding a person to commit suicide in the Bailiwick. Insular legislation could not prevent this and it would therefore fall to the exercise of prosecutorial discretion, although a private prosecution (instituted by e.g. aggrieved family members) could not be discounted. While the small number of individuals charged in the UK have tended to be family members rather than medical professionals, the Committee would have reservations about any local legislative position which may leave local professionals at risk of either criminal or civil prosecution.

Consideration of any potential unintended consequences

As the Assembly is already aware, Health & Social Care experience difficulties in respect of the recruitment and retention of staff. There is an international shortage of nurses and midwives, as well as in specific medical specialisms, and Guernsey is competing in a difficult employment market. The Committee would be concerned that any moves to introduce an Assisted Dying Regime may have unintended consequences in terms of the Island's ability to recruit and retain staff.

Anecdotally, staff have expressed concerns in respect of the possible impact on the relationship between staff, service users and their families should Assisted Dying be introduced. This would need to be carefully considered as part of the development of any proposals so to ensure that this does not impact negatively on the provision of care.

Working party/ resource implications

While the Committee recognises that the working party will be established by the Policy & Resources Committee, it acknowledges that Health & Social Care will need to be a key member of the group. As the Assembly is aware, the Committee has a comprehensive transformation programme and is leading or supporting a further five key policy areas prioritised by the Assembly to deliver the outcomes detailed in the Policy & Resource Plan. Against this backdrop, while the Committee will endeavour to support any working group to the best of its ability, it needs to be mindful of its limited capacity. Further, it is probable, given that clinicians employed by the Committee are unlikely to have experience in Assisted Dying Regimes, that in order to fully explore practical considerations it will be necessary to engage off-island support and expertise to support the group. Although the costs associated with this are unknown, the Committee would not be in a position to fund this within existing resources.

Should the Assembly agree to introduce an Assisted Dying Regime, the Committee may need an increase to its budget in order to put in place the necessary structure. It would clearly be premature at this juncture to seek to quantity this sum as it would be dependent in part on the considerations of the working party and research into the financial impact of assisted dying regimes in other jurisdictions. At this stage, it is uncertain what the short and long term cost implications will be, but these need to be borne in mind.

From the perspective of the Committee, and reflecting on the terms of reference set out in the Requête, particular considerations for the working group, if established by the Assembly, should be:-

- Defining at an early stage the term "Assisted Dying" so to ensure clarity in respect of the proposals;
- To expand their consideration of the role of doctors to include the role of nurses;
- Consideration of the definition of terminal illness. The Committee is conscious that in the course of comparable debates within the UK there has been concern that the definition adopted in respect of terminal illnesses may equally apply to many disabilities, and it is fundamental that any regime fully protects and supports islanders with a disability;
- Equally, the Committee is conscious that any criteria in respect of the availability of Assisted Dying creates an inherent difficulty in focusing on short term prognosis rather than the severity of chronic symptoms. This should not be interpreted as the Committee advocating a system without a six month criteria. This is not the case. Rather the Committee believes that there needs to be a very honest dialogue with the community acknowledging what would be included in any such regime, and by extension, what would not. This should also include acknowledgement of the inherent challenges associated with providing anticipated life expectancies for those terminally ill.

Consultation

The Committee believes that, in making decisions of this magnitude, the Assembly should be aware of the views of professionals and the wider community as part of their decision making process.

On a matter such as Assisted Dying there will always be a range of opinions expressed by health and care professionals, which in itself highlights the importance of a right to conscientious objection by healthcare workers. Due to the limited time available, the Committee has only been able to seek the initial views of a limited number of health and care professionals who may be potentially involved in any future regime. This has, unsurprisingly, indicated a range of views on what is an exceptionally complex and sensitive subject. A more comprehensive consultation exercise should be a central consideration moving forward and the Committee feels that this is best undertaken once

the regulatory bodies have provided initial advice and professionals feel better informed of the possible implications.

The recent tabloid coverage of the Requête illustrates the immensely sensitive nature of the proposals and the requirement for any consultation to be mindful of this. Anecdotally, staff have reported that the media coverage has prompted considerable concern within both areas of the Committee's workforce and, most significantly, its service users. This concern needs to be acknowledged and any subsequent consultation undertaken sensitively and considerately.

Support for Families

Those who oppose Assisted Dying frequently express concerns against the possibility of duress by friends and family. The Committee would not wish to dismiss these concerns, and recognises and supports the need for appropriate safeguards. The Committee would however point out that such "duress" may not come from any form of ill-will or malevolence rather as an expression of grief and concern as they support loved ones at a difficult time. Equally, it is understandable that a dying relative might be concerned about, and indeed influenced by, the impact of their declining health on their family. This has to be understood and openly acknowledged with mechanisms put in place to support both patient and families. This links back to the importance of supporting a culture where people feel comfortable talking about death and what is important to them.

I trust the above is helpful. If you require any further information please do not hesitate to contact me.

Yours sincerely

Deputy Heidi Soulsby
President
Committee *for* Health & Social Care

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19 April 2018

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Dr Peter Rabey
Medical Director
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Dear Dr Rabey

Thank you for your letter to Charlie Massey dated 22 March 2018, to which I am replying in my capacity as Director for Education and Standards. In your letter you asked:

- To what extent is the GMC's position affected by the current legislative framework within the UK?
- Would the General Medical Council consider that participation within a suitable, robust legal regime which enables Assisted Dying – with all the necessary safeguards – is reconcilable with the duties imposed on individual practitioners by the General Medical Council?

The influence of the current legislative framework on the GMC's position

Our guidance does not aim to establish an unequivocal ethical position on permitting or barring doctors from participating in assisted dying. Although the Medical Act 1983 (as amended) gives us the power to advise the medical profession on ethical issues, this is not the same as giving us a general authority to determine public policy on issues that arise within medical practice.

There is also a very practical reason for us not expressing a view on this. We must neither place ourselves above the law, nor condone a criminal offence, and therefore cannot pre-empt the outcome of the parliamentary process. To hold a policy position distinct from the legal position on an issue would make our judicial process untenable. If the law in the UK were to change to allow assisted dying, and we had previously expressed the view that it was morally or ethically unacceptable, we would either be unable to discipline such a doctor, or we would have to set ourselves above the will of Parliament.

The compatibility of assisted dying with current GMC guidance

Doctors who practice in Guernsey are required under Guernsey law to be licensed and registered with us, and must therefore have due regard for the standards we set. Our regulatory approach is UK-specific, and our standards have been developed for doctors working within the UK context. We expect all doctors to act within the law of the country they practice in.

We can therefore understand why there might be concerns about the regulatory risks posed to Guernsey doctors who have a professional obligation to both follow local law and the GMC standards.

Whilst generally we would not consider there to be a fitness to practise concern from a doctor providing services within the legal framework of the country they are working in, we could not give a definitive position at this point about whether or not a doctor could be at risk of fitness to practise action on their UK registration in the situation you have set out. Firstly, we would also need more detail on the scope, limitations, and safeguards of the proposed legislation and how it would be applied in practice. Secondly, were we to receive a concern about a UK registered doctor, we are required by law to consider whether it raises a concern about a doctor's fitness to practise. There are cases where a doctor can justify practising outside of Good Medical Practice guidance and we may take no action; however that is an assessment that needs to be done on a case by case basis.

If there is a specific proposal for how the law on assisted dying would operate in practice, and if it would be helpful to explore what possible regulatory risks might be presented for Guernsey doctors who they require to be GMC registered and licensed, we would be willing to have a further discussion on this.

Yours sincerely

Dr Colin Melville
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Committee *for* Home Affairs

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21st March 2018

Dear Deputy Stephens

Requête – Assisted Dying

The Committee *for* Home Affairs is grateful for the opportunity to comment upon this Requête. It fully appreciates the sensitivity of this matter and the genuinely heartfelt views around it which are held by some. It is however an undeniably complex matter which does not lend itself to quick or easy solutions.

The proposal is of direct relevance to the mandated responsibilities of the Committee which include the preservation of life, through emergency responses, and the legislative structures of justice where-in it is laid down that no one shall take, or assist in the taking, of another's life.

Clearly there are always moral and ethical exceptions which our current legal framework makes allowances for. An example being where a medical professional has to take incredibly difficult decision to turn off a life support system. However, it is the Committee's understanding that regardless of what legislation the Bailiwick might choose to put in place it will not change the law in the UK. Under the UK legal system the taking of life by a British Subject can be investigated, tried, determined, and punished in England and Wales, regardless of where in the world the killing took place. Again even the definitions of British citizenship and British subject are not straightforward but for British nationality purposes Guernsey is deemed to be part of the United Kingdom. Thus potentially any Guernsey resident assisting another to die may find themselves at risk of punishment at the hands of the UK courts.

The above gives a clear signal that with such a fundamental life and death issue it would be extremely problematic for Guernsey to pursue a course of action without the UK having already having taken the same decision and moving to amend its laws accordingly. In this respect to seek to introduce assisted dying locally will require significant staff and

legal resources for a matter which the States has not categorised as one of its priorities within the Policy & Resources Plan.

Yours sincerely

Deputy Mary Lowe
President
Committee *for* Home Affairs

Committee *for*
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Our Ref:
Your Ref:
Date: 04 April 2018

By e-mail

Dear Deputy Stephens

Consultation on Assisted Dying

Thank you for the opportunity to comment on the Rêquete regarding assisted dying. We understand that the views expressed by ourselves and other stakeholder Committees will be included in a letter of comment prepared by the Policy & Resources Committee.

We are aware that the outcome of this debate may have an effect on our budget, but we do not anticipate the financial impact will be substantial.

As a Committee we have no advice to provide to the States at this time. However, we look forward to being consulted during the policy development process should the States adopt the Rêquete's propositions as resolutions.

Yours sincerely

Deputy Michelle Le Clerc
President