5 June 2014

By email - Healthandsport@scottish.parliament.uk

Health and Sport Committee
T3.60
Scottish Parliament
Edinburgh
EH99 1SP

Dear Sirs

Please note our formal response to the Assisted Suicide (Scotland) Bill.

**Background thoughts**

- **Do we need this Bill?** We currently have a legal system where individual situations can be raised and brought to legal debate.

- **Our belief is that hard and/or emotional cases do not make good law.**

- **Current provision of high quality palliative and end of life care in Scotland is not as it should be, not available to all regardless of diagnosis, age or geographical location.** (Audit Scotland, 2008), Living & Dying Well Reflecting on Progress (2011), Are We Living & Dying Well Yet? (2014). Quality is variable, Quality Indicators have not yet been established in practice, the majority of people living with a diagnosis of life limiting illness do not have their palliative needs identified and are not on a Palliative Care Register (Mare Curie, 2014).

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**Key findings**

- Most patients were identified for palliative care too late to fully benefit – on average only eight weeks before dying.

- GPs said that introducing palliative care was fairly straightforward for those with cancer, who typically had a clear terminal decline but much more difficult for patients with other life-threatening illnesses.
Some GPs found it difficult to raise and discuss death and dying with patients, particularly with patients with a non-cancer diagnosis.

Both patients and health professionals struggled with understanding of end-of-life/palliative phrases, further confusing the issue.

The study concluded a gradual and long term approach to phasing-in supportive and palliative care while continuing with other treatment care planning would benefit patients and their families.

Peter McLoughlin, co-author of the report from NHS Lothian said:

“Health and social care professionals in all settings across Lothian already offer supportive care throughout the patient pathway from clinical assessment, to diagnosis, treatment and follow-up. The findings from this study emphasise that many more people, especially those with non-cancer conditions, may benefit from a more explicit recognition of palliative care needs, at an earlier stage in the pathway, as part of care planning.”

Historical context of shifting balance/slippery slope.

Abortion Act, 1967 was amended. In May 1998 the Acts Amendment (Abortion) Act 1998 (WA) was enacted. It amended the Criminal Code 1913 (WA) (“Code”) and the Health Act 1911(WA) (“the Health Act”). In 1967 two medical practitioners were required, which was changed to 1.

Liverpool Care Pathway (LCP) was introduced to provide guidance and support to Health Care Professionals within the Acute Setting, caring for patients in the last days of life and their families. This was then transferred to other care settings without the key education and training always being in place resulting in a public outcry and situations of ‘premature dying’. The tool was allegedly used inappropriately and did not always result in a ‘good death’.

We believe it is morally wrong to advocate the life of another being ceased prematurely and most especially in the circumstance of Assisted Suicide.

It is a crime to commit a murder, yet to assist a person who is seriously/terminally ill to die will be acceptable and not against the law.

The introduction of this Bill will lead to societal and healthcare decline.

There is no evidence of how this people, processes and quality of care/service will be regulated. Will this come into the remit of Healthcare Improvement Scotland?

This is, in our opinion, the completely wrong message, philosophy and vision of an Independent Scotland.
We should ensure every person diagnosed with life limiting/shortening illness has everything they need holistically to optimise quality of life and offer psychological support in instances where quality of life is perceived not to be good.

- How will we safeguard against ‘tourism suicide’ – inevitably this will happen one way or another.

- Age 16 is not the ideal age for either a person to decide to die nor assist another person to die.

- The Yes and No Campaign have debated the age to vote in the referendum which has identified legitimate mixed view.

- Where will assisted dying unfold
  - Home or ‘dying places’?
  - Wider impact on community – Good Life Good Death Good Grief

- There will a consequence to informal and professional carers/GP/Community Teams if they are to participate or care for those who wish to end their lives prematurely (Peirpoint 2005, the last hangman)

- The Bill states a person has capacity to make a request if the person –
  - Is not suffering from any mental disorder (within the meaning of section 328 of the Mental Health (Care and Treatment) (Scotland) Act, 2003 (asp13). Our experience of the patient and family population using Hospice services is often of underlying non-diagnosed mental and psychological illness, as well as learning disability. These are exceptionally vulnerable people who would have a level of capacity in terms of deciding what to eat, drink and wear each day but not fully understand the consequence of behaviours, relationships and issues specific to optimising quality of life and whilst one could have a one off conversation and believe the person to have full cognition, upon further development of relationship and getting to know, then realise cognition is compromised in some way but it would be a purely subjective experience. Who would protect these people? Often these people are supporting and/or the main carer for a person living with life limiting/shortening illness and are unwell themselves, so would grief be taken into account?

- Life shortening has no definitive timeframe
  - A person could have gone on to live for many years – contributed to society, family, community life and overall societal development.
  - Until palliative care is an automatic right of every person living with the diagnosis of life shortening/limiting illness – the Bill should be discouraged.

- Questioning the role of hospice
  - Who will care for those where attempt has failed?
Currently in Holland those who experience a failed attempt are euthanased. This is a very different Bill so how will this unfold in Scotland.

- If a person is not euthanased, what is the projected cost of care?
- Who will cover these costs – the current Tax Payer?
- Could our current Healthcare system cope with this consequence?

Response to Consultation Questions

Q1 Do you agree with the general purpose of the bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?

- No – we believe this an overt insinuation that living with and/or caring for a person living with a life shortening illness has associated burden.
- In our experience and learnings from cases of Assisted Dying/Suicide within European Legal States, the bereavement risk for those on-looking to the situation is and will be immense.
- Can our system cope with an increased number of people living with compounded/complex grief? We have no robust evidence based, equitable provision for bereaved people currently. How will we cope with an increase?
- People may request such action when at their lowest ebb psychologically and when they are:
  - Not depressed
  - Not without capacity
  - Not living with a mental illness
  - Symptomatic with non-identified symptoms
  - Not in receipt of high quality palliative care, either through their needs not being identified or poor quality care experience by both health and social care practitioners.
- Following diagnosis of life-shortening illness, people speak of feeling vulnerable, life never being the same due to physical, emotional, spiritual and societal change. Unless appropriate measures are put in place, this diminished self-worth and increased vulnerability could contribute to such a request.
- The 24 day time period from initiation to fulfilment (24 days) would sadly capture those ‘crying for help’! Screening for ‘crying for help’ can take many months to uncover, therefore there is thought these people could be dead before capture.
- Currently the Scottish Government is investing millions of pounds in Suicide Prevention Campaigns and infrastructure to prevent a person from taking their life (Erskine Bridge) yet by supporting and/or introducing this Bill, will be happy to counterbalance this by spending millions assisting people to commit suicide – a confused, paradoxical Parliament and Government indeed!
- This gives a very mixed message and diminishes the value of human life.
- Has the public been involved in this consultation? Are they aware of the full detail? Do they know what this involves?
- Have those currently living with life shortening illnesses had the opportunity to be openly questioned of their intention or potential intention, and if so which illnesses are
those people living with – Malignant/Non-Malignant – further research is required to fully establish the need for this Bill for those living with the identified illness, it is not, in our opinion appropriate to seek the views of the ‘well’.

• Those living with serious illness/life shortening/terminal, have the means to take their life/commit suicide and currently don’t – what is this telling us?
• Mixed message.
• Diminished value of human life.
• Has the public been involved in this consultation?

Q2 Do you have any views on how the provisions of Bill, compare with those from the previous End of Life Assistance (Scotland) Bill?

• There is no mention of alternative approach/models of care.
• All definitions have been written in a palatable manner – appealing and manageable.
• We believe the 14 day time period is too short.
• This is equivalent to a palliative care emergency such as catastrophic haemorrhage or Superior Vena Cava Obstruction, yet there is no mention of Specialist Palliative Care involvement/referral prior to initiation. This would seem a logical first step to ensure needs and symptoms had been screened and option appraisal presented from key experts and specialists

Q3 The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to comment on this?

• Currently our system is bulging with situations where process and requirements should have been adhered to:
  o Financial structures
  o Legislation and practices surrounding Immigration
  o Benefits system
  o Medical system
  o Church state
  o Political Systems e.g., MP/MSP expenses
• People who know what is right and wrong, have selected to do wrong, thinking they would not be caught or the general public would be outbalanced by their power, so there is ample evidence of the difficulty there is within our modern culture to sustain justice.
• Who would regulate this? Would situations occur where investigation would take place following the death of someone who should not have actually died? In this case, how many would be too many to suggest the law is flawed? Is this not a good argument for status quo where those who wish to die prematurely have the right to present their case to court rather than change the law for all? Who would gather statistics and experiences of mistakes, those who died who shouldn’t have?
• What ‘safeguards’ will be in place to prevent another Shipman experience.
• There remains a significant number of ‘lone’ GP’s which was a firm recommendation for change. This change has not occurred.
• The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to comment on this?
• The opt in / opt out system
  o How will professional systems and families keep up to date with changing minds?
  o Will this information be shared via eKIS (electronic Key Information Summary)? If this is the case, GP’s would be openly questioning patients and actively screening patient’s wish which is paradox of the current system where not all patients are offered or screened for palliative care input!
  o Currently the Key Information Summary does not contain the most up to date information on current patient situations to support decision making (professional communication systems poor), so there is little confidence information would be shared timeously within the number of days specified within the three stages and the overall 24 day period
• What mechanism will be in place to assure families that all possible options were offered, explored and appraised?
• Will families and those caring for the person have the right to this information at the time the person is making their request?
  o Data protection?

Q4 The Bill outlines a three stage declaration and request process that would be required to be followed by an individual seeking assisted suicide. Do you have any comment on the process being proposed?

• What assurances will be in place to ensure the process at the outset of the Bill would not be amended in parliament at a later stage?
  o The Abortion Act 1967 is a prime example of amendment post implementation of the Act.
• The 24 day time period is too short
• Changing our mind?
  o How do we make our voices heard when we are ill and/or fearful? Who listens? Currently there is no provision to ensure care is delivered according to the preferences and wishes of the patient – should this not be our starting point? Who will hear the voice of the voiceless!
• Costs of staying alive v costs of Assisted Suicide
  o Are we ready and willing to pay the real cost to humanity / our financial structures / the decay of healthcare systems and the quality of our Professions, as well as the fabric of our society
• Currently the cost of delivering high quality palliative and end of life care has been determined as too much/too expensive – Living and Dying Well was attributed £3 million to support the development of a completely new caring structure – was this was set up to fail!!! This funding in the majority was given to Primary Care which is not where the majority of people die in Scotland. Was this wise?
Q5 Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life shortening illness, or a progressive condition which is either terminal or life shortening?

• What is life shortening? - there is such debate currently surrounding trajectory and prognostication as underpinned by research cited in example 1 & 2, specific to why people are not referred timeously to palliative care / Specialist Palliative Care / placed on Palliative Care Registers yet we are to believe professionals will become experts at determining who has life shortening / terminal illness. If they will have the ability to do it then – why not now? Let’s correct the correctable! Invest in education of professionals to help identification and have people cared for by experts when they are diagnosed with life limiting illness, not generalists who may never have the desire to know.

• Patient cognition can fluctuate for medical reasons in such a subtle manner. Assessing capacity is most challenging in usual circumstances, yet progress and progression through all the three stages is capacity dependant. Our concern is for those who, due to this, will slip through the net. Is one too many?

• Decisions could be based on fear and the challenge of living with uncertainty
  o What will happen next?
  o The dying process – what does a natural death involve – have previous death experiences with family members been good or bad experiences?
  o Will I be cared for by people who care about what they do, those with the correct skills, knowledge or expertise, or will I be one of the people as cited in the Neuberger Report, cared for by people who were not competence, skilful or confident in the delivery of high quality palliative and end of life care?
  o Healthcare Improvement Scotland and the Care Inspectorate have highlighted poor care environments resulting in a depletion of public confidence. If current regulation cannot foster the change required, how will those bodies regulate this service to the correct standard?

• Not all professionals have the correct level of understanding/empathy of how it feels to be ill, change that takes effect following diagnosis, therefore it is our opinion, these professionals would be unable to challenge the decision making process underpinning initiation of Assisted Suicide. This requires a skilled approach at an advanced level.

Q6 Are you satisfied with the eligibility requirements as regards age, capacity, and connection with Scotland as set out in the Bill?

• Has the following been considered
  o Capability differences / capacity issues / mood changes
  o The consequence to parents and families of young people

• Young people live with varying thoughts and interpretations of quality and meaning of life? What age does adolescence end for a young person? New evidence suggests 28 years for males?

• Issues with the role of the Licenced Facilitator, especially if the minimum age will be 16.
• How would the ‘connection to Scotland’ be regulated?

**Q7** Do you have any comment on the roles of the medical practitioners and pharmacists as provided for in the Bill?

• Should the prescriber be a Medical Practitioner/Prescriber?
• Have individual Pharmacists as businesses been included in this consultation?
  o Will this service be set up in a similar way to Methadone Clinics?
  o Will a person carry the substance on their person in the street – from pharmacy to home?
• Suggestion of involvement of Medical Practitioners in the Assisted Suicide of a citizen is against the Hippocratic Oath
• Should this be done as a group – Analogy Termination of Pregnancy Clinics
• Opt In / Opt Out as a prescriber, carer, pharmacist, and paramedic – how will a resource effective shift rota be created to include those opting in and out?
• MCCD – Medical Certification of Cause of Death will require an Assisted Suicide Box/Section
  o Will this evoke referral to the Procurator Fiscal?
  o Will a new review system will be required for deaths as a consequence of Assisted Suicide?
• Where will Assisted Suicide take place?
• Currently those who wish to die at home don’t and can’t, so how will this unfold within the community setting? Why can’t we invest in the correct resources to ensure anyone who wishes a natural death at home can? This would be a good starting point.
• Surely we should not focus on the development of new resources for a particular population of patients living with life limiting/terminal illness, when we have not put the correct resources in place for those dying at home now.
• Professional boundaries will be eroded and destroyed – who will the trusted be?
• Therapeutic relationship will be compromised through a practitioner being in agreement or against. Either way practitioners will be a disappointment either way.
• The outcry following LCP investigation / Neuberger Report findings / response by families should be read and adhered to. People generally do not wish life to end sooner than it does; therefore it seems ironic to allow a very ill person the right to die when everything about life will have changed. Are we at our best to make decisions then?
• Destruction and disparity will be the consequence when some do and some don’t – the will be an impact on recruitment and retention of HCP’s
• Is it then the default that good palliative care is the 2nd method of dying – this is a danger

**Q8** Do you have a comment on the means by which a person would be permitted to end his/her life under the Bill?

• One would be informing the patient on how to die
  o Is this ethical or legal?
  o This is the equivalent of advising an IVDA of which veins to use for greatest impact... it cannot be acceptable for one group and not others...
• Methods
  • Death should be dignified and respectful, how can this be assured
• Side effects
  o How will these be avoided?
• Gentle & Easy
  o Do we wish to use this as the description of a death from suicide? Is this the current experience? Have we asked these questions?
  • What will the backup / contingency plan be if there is a failed attempt or if at the last minute the person changes their mind
• Has the impact on Scottish Ambulance Service / Emergency Care Staff / Funeral Services / Chaplaincy Service – those comforting the wounded been considered
• Will a 2nd / 3rd or 4th attempt be permitted
  o Will a person be euthanased as happens currently in Holland and Belgium?
  o Who will euthanise – will this be the LF?
  o How will we know the person had a failed attempt and wasn’t just euthanased from the outset?
• What support will be in place if declined

Q9 Do you have a comment on the role of licenced facilitators a provided for in the Bill?

• Is this a role we wish to nurture within our society?
• What will happen when our children or family members choose this as a career choice?
• Where will these roles be advertised?
• How will recruitment of LF’s be undertaken? Who will the interview panel be? What skills, qualities and attributes will LF’s require? Will there be a job description? Who will pay LF’s and provide the structure of support? How will ‘fitness to practice’ be assured? How will LF’s be appraised? What will the cost of employing LF’s be? Will they contribute to the national pot – become a tax payer? Will this become a career?
• Will there be a fee to die?
  o To the person and/or family?
• Will there be one facilitator per death or two?
• How will we safeguard the community from LF’s, from a Peirpoint perspective and from anecdotal evidence from Death Row Governors and Executioners.

But on a more practical level, any debate over the efficacy of the death penalty should also include a discussion of the enormous psychological toll capital punishment takes on jurors, Justices, Governors, and even executioners. These individuals have been speaking out with greater force recently about how it feels when the responsibility of taking the life of another person falls on the shoulders of an individual. Corrections officers undoubtedly have stressful jobs. One recent report indicates that 31 percent of correctional officers have post-traumatic stress disorder (PTSD). Comparing that to the rate of PTSD among returning Iraq war veterans, which is 20 percent, illustrates the enormity of the psychological toll exacted on prison staff. For those charged with carrying out executions, the toll is even heavier. - See more at: http://verdict.justia.com/2013/10/25/weight-capital-punishment-jurors-justices-governors-executioners#sthash.z7wABRrU.dpuf
• Deteriorating mental state – over exposure to macabre dying / profound existential issues both in life and death
• Evidence based increased use of drugs and alcohol as mechanisms of coping
• What will the role of the LF be in the situation of medication being dropped or for some reason the patient is unable to hold to their mouth for the length of time required
• What will the role of the LF be in the situation of ‘failed attempt’, will they resuscitate and call 999 for emergency services
• How will a LF sustain competence and keep up to date
• What will the minimum academic requirements be?
• Will professional bodies (GMC, GMC, HPC, BACP support those with a healthcare background)
• How will code of conduct of each profession be affected?

Q10 Do you have any comment on the role of the police as provided for in the Bill?

• How does Police Scotland feel about this Bill?
• Have we considered their moral stance on such issues?
• How will shift patterns be negotiated to honour the professionals who wish to opt out?
• There is an evidence based national reshape of Police on the streets, how will Police support this level of community dying? Will they be told in advance of the person’s intention? How will minimise the risk of wrong doing? How will these deaths be investigated?
• Will they be responsible for removing unused drugs? Will this be role of the LF?
• What training will the Police receive on the intricate details of Assisted Dying and the role of the Licenced Facilitator?
• What support will Police offer the family of the person who has died?
• Will their approach differ to current practice when a person dies prematurely?

Q11 Do you have any comment to make about the Bill, not already covered in your answers to the questions 1 – 10?

• The fear of legislation creep
• Dying is not black and white – assisted or natural
• No-one can decide when another should die
• Why should dying be different to other life events where significant adjustment is required
  o Spinal injury
  o Amputee
  o Service man/woman returning from military duty with life altering physical and emotional states
• What will happen if a HCP declines/refuses to treat the person living with desire to die – Assisted Suicide
• How will we safeguard situations where care delivered across health and social care systems are so poor, where a situation is made untenable for those living with life
shortening / terminal illness? This is a major contributory factor underpinning support for this Bill. It cannot be that poor care standards make this an option.

• Current lived experience of poor care delivery within acute settings – families begging the hospice to take the person – people being genuinely terrified of being cared for within a care home. This will force decision making – forced dying

• Currently there is no consistent public resource allocation or investment in educating the public on death/dying or hospice care – there is no government support for promoting hospices or Good Life Good Death Good Grief. There are many national campaigns but none promoting the benefits of natural, safe dying. Are we worried we cannot provide this? Is our system not good enough for natural, safe dying? Would it be more cost effective for people to decide to die sooner? What does this say about our NHS – Cradle to Grave?

• Where will people go when they are living with irreversible brain damage due to hypoxic state as a result of failed attempt – who will pay for their care

• Will this become a business?

• There are varying differences between intolerable and inconvenient

**Underpinning Evidence relating to “Slippery Slope”**

Doctors in Belgium are killing an average of five people every day by euthanasia, new figures have revealed.

The statistics also show a huge 27 per cent surge in the number of euthanasia cases in the last year alone.

The soaring number of deaths will inevitably fuel fears that euthanasia is out of control in Belgium, a country which only months ago became the first in the world to allow doctors to kill terminally ill children.

There has been a surge in the number of euthanasia deaths in Belgium since it was legalized in 2003. Earlier this year there were protests to stop the law being extended to children?

The figures, published in Sudpresse, Belgium’s leading French-speaking newspaper, showed that 1,816 cases of euthanasia were reported in 2013 compared to to 1,432 in 2012, an overall increase of 26.8 per cent.

‘You could say that currently there are 150 cases of euthanasia per month in Belgium or, even more telling, five people euthanased a day,’ the newspaper said.

Of the total number of cases in 2013, 51.7 per cent were male patients and 48.3 per cent were female.

Elderly people aged between 70 and 90 years made up just over half (53.5 per cent) of the total. Those aged between 60 and 70 years represented 21 per cent and those aged over 90 years seven per cent.
The under-60s accounted for just 15 per cent of the total number of cases.

In 2003 Belgium was the second country in the world to legalize euthanasia after Holland liberalized the law a year earlier, becoming the first country since Nazi Germany to permit the practice.

Over the past decade the numbers of Belgians dying by euthanasia has crept up incrementally.

Controversial: In February, the Belgian House of Representatives voted in favour of extending the policy to children who are terminally-ill or in a state of unrelieved suffering.

There was a 25 per cent increase in the number of euthanasia deaths from 2011 to 2012, soaring from 1,133 to 1,432, a figure representing about two per cent of all deaths in the country.

In February Belgium extended euthanasia to children who are terminally-ill and in a state of unrelieved suffering.

They must also be judged to have ‘capacity of discernment’, affirmed by a psychologist, and the consent of their parents before they can die by injection.

Anti-euthanasia campaigners have argued that such safeguards have consistently proved to be meaningless.

They say that besides patients who are gravely ill euthanasia is used increasingly on people with depression or non-terminal conditions.

Those killed include deaf twins Marc and Eddy Verbessem, 45, who were granted their wish to die in December 2012 after they learned they would likely to become blind.

Last year Nancy Verhelst, 44, a transsexual, was also killed by euthanasia after doctors botched her sex change operation, leaving her with physical deformities she felt made her look like a ‘monster’.

Disability rights campaigner Nikki Kenward of the UK-based Distant Voices pressure group said the figures demonstrated the difficulties in regulating euthanasia.

She said that once a country legalized assisted suicide or euthanasia people were inevitably killed in greater numbers than ever envisaged.

The figures should serve as a warning to the Parliament not to change the law on homicide to allow even assisted suicide, she said.

‘As the numbers of people dying from euthanasia in Belgium grow, that slippery slope comes into vision,’ said Mrs Kenward of Aston on Clun, Shropshire.

‘I am vulnerable,’ said Mrs Kenward, who has been in a wheelchair since the 1990s when she developed Guillain Barre Syndrome.
‘I’m afraid of becoming another statistic, another faceless victim,’ she said, adding: ‘We are told that safeguards will protect us from abuses. They certainly do not protect the elderly in Belgium.’

By Simon Caldwell
Published: 16:53, 28 May 2014 | Updated: 18:24, 28 May 2014
I support the St Margaret of Scotland Hospice response to the Health and Sport Committee Consultation on the Assisted Dying (Scotland) Bill.

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