Proposal for Right to Palliative Care by Miles Briggs MSP
Consultation Response by [REDACTED]

Introduction
In support of your Proposal it has been suggested that I share with you our experience as a family over the failure of the Health and Care Partnership in [REDACTED] to provide palliative care at home to my wife [REDACTED]

Background
In late September last year my wife [REDACTED] was discharged by the Consultant at the [REDACTED] back to the local medical and social care team for palliative care at home as they felt that no more treatment they could provide would benefit [REDACTED]. She had been a patient with them for around 20years with the condition [REDACTED] which had become worse over 2023 particularly in her [REDACTED].
[REDACTED], who had worked in the Health Service for many years, felt very strongly that she would wish to die at home and our understanding was that palliative care at home would be provided.

I felt by describing what happened to and didn't happen for [REDACTED] might illustrate the current unacceptable state of palliative care in the community, in particular in [REDACTED] but more generally in [REDACTED] and I suspect in many but not all parts of Scotland.

Description and Timescale of Events – Social/Personal Care & Medical Care

1.Social/Personal Care
In the first week of October we were contacted by Social Care to say one of their officers would be visiting on Monday [REDACTED] October which she did. She explained the options open to us under the [REDACTED] Health and Social Care Partnership's Self-Directed Support arrangements in line with The Social Care(Self Directed Support)(Scotland) Act. Because of the situation and our lack of knowledge and experience of arranging care we opted without hesitation for Option 3 where the support is arranged and managed by the Council. So the officer undertook to arrange personal care support from the following Monday [RERDACTED]. As the week went on however, the officer was in touch several times to say they were having difficulty arranging carers and it became clear that by the Friday they would not be in a position to provide the care from the Monday as they undertook. As we have subsequently found out the Council, other than a very small team to deal with particular emergencies, rely on outsourcing care to specialist care companies none of whom could respond to the Council's demands on behalf of [REDACTED]. Research we have subsequently done as a family has found that none of these companies were in a position to provide the level of services required and the Council knew or should have known through normal procurement procedures ,depending as they do, on outsourcing care.

Over that weekend the family searched hard for carers and by luck an experienced carer moving through from the [REDACTED] had an advert in the [REDACTED] newsletter advertising her services from November. Nonetheless we contacted [REDACTED] and explained our desperate situation, she came to see us that evening and started the following morning albeit she was not intending to start work till after her holiday on week commencing [REDACTED]. During that week we were further able to find another experienced carer through a recommendation by a neighbor . [REDACTED] again responded immediately, covered the week [REDACTED] was on holiday and then [REDACTED] and [REDACTED] attended on a rota basis to care for [REDACTED] in conjunction with my two daughters who made special arrangements at work and home to support us.

I only include this level of detail to illustrate that it was only by luck and personal research we were able to provide the support to [REDACTED] which the Council should have had arrangements in place to provide.

Under this Option (1) where the family arrange the care, the Council are meant to make Direct Payments to 'fund the provision of your support '. Three weeks after [REDACTED]'s care started we eventually received details of how we should go about claiming this Direct Payment. This consists of setting yourself up as an Employer with all the employment and other regulatory obligations that go with it. Given by this time we as a family were flat out with the help of our two carers in looking after [REDACTED] night and day as of course by this time she was bed bound. We therefore replied to the council we were not in a position to make these demanding arrangements and arranged with them to make the claim retrospectively.

[REDACTED] passed away 2 weeks later on the [REDACTED] November . We opened up dialogue on reimbursement of costs with [REDACTED] following [REDACTED]'s funeral and while we have now received a so called discretionary payment, which is in effect what we should have been paid from the beginning, it falls well short of the full cost. However in the bigger scheme of things that is less of an issue in our dispute with the Council which is still ongoing and which is covered later.

The bigger general issue here is that as a family we were both able to advance fund the payments to our carers and supplement their professional care as assistants so we were able to manage with only one carer at any time. Our concern now is more how do families without our resources manage?

Ongoing dispute with Council over their inability to provide care and to obtain reimbursement of our costs

I will cover this very briefly as it is still ongoing and I have had to refer it to the Chief Executive as we were unable to get fair reimbursement of our costs and get the Council's Social Work Department to accept responsibility for their failure to make adequate provision to provide adequate care in the Palliative situation. Also to reimburse us accordingly.

We have asked the Chief Executive to carry out an investigation and he has eventually referred it to the Team Leader of his Complaints Team . While we have no expectations of further reimbursement of our costs we, in conjunction with our Councillor ,who has been supportive throughout, want to get to the bottom of the situation with regards to [REDACTED]'s lack of care,to improve the situation for the people of [REDACTED] in the future.

2. Medical Care.

In discharging [REDACTED] for palliative care in the community, the [REDACTED] Consultant's expectation was that there would be a specialist, dedicated palliative care team to work in conjunction with our GP and his local Health Centre Team. Such does not exist in [REDACTED] and perhaps not across the whole of the [REDACTED] Health Board Area.
So it was left to our dedicated family GP to work alongside our heavily committed NHS District Nurses to see to [REDACTED]'s medical needs.
Our longstanding family GP was absolutely committed to providing [REDACTED] with the best medical care he could coming in every other day including weekends . As we have known him for many years this was also a very helpful 'psychological/moral ' support for [REDACTED] and us all as a family too. The District nurses too were very attentive too but until the last week really on a reactive basis.
We understand there used to be a team of palliative care nurses in the past but this was disbanded.
The Macmillan Nurses from [REDACTED] also visited once and kept in touch by phone but were really only there on an advisory basis and not in anyway hands on. We understand we could have contacted the Marie Curie nurses to give us some respite support overnight but we decided we could cover that within the family.

Conclusions
In circumstances like [REDACTED]'s and us as a family, a coordinated and planned arrangement for Palliative Care at home is absolutely essential and as it avoids any form of hospital or hospice involvement would have thought was financially more viable for the Government. However, certainly in [REDACTED] and I suspect in many other areas of Scotland this arrangement does not exist. I am not convinced this is totally a question of cost and level of resources. I did not find there was the right attitude or knowledge at management level in either the Council or the Health Board. To claim there is a Health and Social care partnership is very misleading. A Director of the Partnership explained it was a strategic Board to manage and coordinate the resources of the Health Board and The Council. Well it doesn't!!!

I therefore totally support the Proposal to a Right to Palliative Care and would be happy to provide any further information or support to make it happen.

Good Luck Miles!

REDACTED