Subj: **Haemophiliac widows/carers rights**
Date: 26/07/2005 13:45:12 GMT Standard Time
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For your information

25th July 2005

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RE SUMMER PAYMENT

Dear Mr Harvey,

I am writing with regard to the Macfarlane Trust summer payment following our telephone conversation of 25th July. As you are aware, several haemophiliac friends rang me over the week-end to check that I would be receiving the £750 summer payment that my husband Peter would have been entitled to had he not died in April this year as a result of receiving contaminated NHS plasma. Peter is the second family member to have died in this way!

My understanding was that as a new widow I would be entitled to whatever Peter was entitled to at the full rate for at least six months plus additional payments but I have not received a letter regarding the summer payment and wonder if insult is to be added to injury by excluding me from this allowance. I will never be able to put into words properly my feeling of utter devastation at losing my husband, my best friend, and soulmate, and I cannot understand how the government can have so little compassion for all the widows who have given up so much in so many ways in order to care for their husbands.

I have gone from a reasonable joint income with Peter where he received DLA at the higher rate, Mobility Allowance, and Income Support with all its added benefits, plus the Macfarlane Trust money, to just £57 a week Incapacity/Widows Benefit, excluding the short term Macfarlane Trust payments which continue for only six months. I am now suffering from severe asthma attacks, and have to use a nebuliser and steroids plus three inhalers. According to my GP, my ill health now is as a result of the stress endured in caring full time for Peter combined with intensive campaigning for the rights of the haemophilia community. Who will compensate carers for any ill health they suffer as a result of long term caring for their husbands? I am sure all the widows feel that the way we are left financially after our husbands have died is totally unacceptable. Six months payment following bereavement balanced against many years of caring full-time is totally unacceptable. Who is fighting our corner? Why are carers/widows only ever seen as an appendage of our husbands and not as individuals in our own right. There should be proper care of the affected as well as those infected. There is a serious imbalance here!

The government is treating widows as second class citizens as was the case in Victorian times, discriminating against women. The carers of haemophiliacs are predominately women, and I do not believe that if it were the other way round with an illness affecting mainly females that men would be expected to give up their careers so quickly. We are not in the Dark Ages, times have moved on with equal rights for women, so why is the Macfarlane Trust set up in such a way that only the issues affecting the men are recognised? Our men are infected and their lives seriously affected, but the lives of the predominantly female carers are seriously affected as well. The government must now recognise what we have given up in our own right in order to care for our husbands. I for one have lost the right to have children without fear of infection, a career, pension rights, and a yearly salary

NOT RELEVANT

which was £23,000 a year well over a decade ago, I have also lost my good health!

Here are some basic facts about carers. Carers save the country /government £57 billion every year. Over I in 5 carers spend over 50 hours a week on their caring responsibilities. Over two thirds of carers believe their health has been adversely affected as a result of their caring role.

May I suggest that you ask each widow to calculate the cost of 24 hour care at an hourly rate over the period of how ever many years they have cared for their husbands and present this to the government who should be providing us with a proper widows' pension until we die or re-marry. This is the case for widows of servicemen killed in action, and police widows. What about the widows of haemophiliacs who died as a result of NHS treatment, who cares for us? Carers save the government billions of pounds each year, yet there is hardly any money there to help us when we need support. Haemophiliacs would have cost the government a fortune in 24 hour nursing care if we carers had refused to look after our loved ones ourselves. In most cases our husbands wanted to be cared for by their wives/partners, yet we are not supported in this role. We are left feeling used and uncared for after our husbands die. Perhaps the government would care to pay us for the care we have given at the same hourly rate that would be given to an employed carer of a haemophiliac. I am seeing my MP Jim Cousins on this matter, and would be more than happy to assist the Macfarlane Trust with a proposed package for widows to be presented to the government after the summer recess.

Well I for one value the input of other widows and I in caring for our husbands and partners, and want this recognised by the Department of Health. If carers themselves believe we have no value then no-one else will value us. Can you advise me what is being done to fight for a care package for widows in their own right?

I would ask that the Trust extend the summer payment to widows as well as those infected, this would at least be a starting point in the fight for widows to receive a reasonable level of financial security which we don't have at present. Our husbands could not get life insurance and went to their deaths worrying about how their wives would cope not only emotionally but on a financial level as well.

I am not going to apologise for speaking out for widows' rights. I will continue to campaign on this issue and request that you ask the Department of Health to meet with a group of us as soon as possible in order to address our needs. There is supposed to be a Minister with responsibility for carers, what contact has the Macfarlane Trust had with this person to champion the rights of carers and to discuss support to long -term carers who suffer bereavement and must return to work? Wives and widows are fully recognised in the Eire recompense package, what about us? What is so different about us? Why are we suffering discrimination? Please forward this letter to the Department of Health. Do I have to use the Human Rights Act and go to court on this issue before our rights as carers/widows are recognised?

Yours sincerely

Carol Longstaff